## A NICE Approach to Combining Micro and Macro Conceptions of Deliberative Democracy

## Volume 1

## Lauren Johnston

Doctor of Philosophy

School of Geography, Politics and Sociology

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#### Abstract

Deliberative democracy is a model intended to produce rational and well-reasoned decisions by bringing together those affected by decisions to deliberate about the issues. There is a growing interest in how deliberative democracy can be institutionalised however there are challenges associated with this. The primary challenge for deliberative democracy relates to scale (Parkinson, 2004). At a macro level, it is practically challenging to involve all those affected by decisions in meaningful deliberation in an equal and inclusive manner (McLaverty, 2014, Chappell, 2008, Young, 2001). Even at a micro level, these challenges still exist due to inequalities in complex societies. As a response, Hendriks (2006) argues that by combining micro and macro conceptions of deliberative democracy, standards of deliberative democracy can be better achieved. One institution which could practically combine the two conceptual approaches is governance networks. This is because they can use deliberative approaches (Papadopoulos, 2012, Dryzek, 2011) in decision making and some embody the principles of deliberative democracy (Atkins, Smith, Kelly and Michie, 2013, Daniels, 2008, Gutmann and Thompson, 2002). Networks are used by governments to help solve complex problems by bringing experts and those with specialist knowledge to the process. However, some networks lack democratic accountability because they are often elitist (Hendriks and Boswell, 2015, Papadopoulos, 2012) and as a result suffer from legitimacy problems.

Through case study research, this thesis will explore if governance networks can combine micro and macro conceptions of deliberative democracy to enhance their democratic governance. In doing so, the research will measure the quality of deliberation that takes place in the National Institute of Health and Clinical Excellence (NICE) which is a quasi-autonomous national government organisation and operates as part of a large healthcare network. Through interviews with committee members the research will also assess how networks deliberate at a macro level.

The committee meetings in NICE has been described as high-quality expert deliberation (Moore, 2016). However, the meetings were exclusive as members were largely experts from the medical field with little citizen or patient involvement. There were some instances of macro deliberation taking place outside NICE PHAC meetings but it lacked wider public deliberation inclusive of a variety of deliberative spaces. Moreover, there were very few examples of micro and macro deliberation being integrated. The research concludes that NICE do have the potential to build on the deliberative foundations by being more active in integrating micro and macro deliberation through designed coupling (Hendriks, 2016) and using bridge-builders as aids to coupling. By applying some of these recommendations, NICE could become more deliberative, democratic and accountable. This might also apply to similar networks who are interested in institutionalising deliberative democracy and overcoming their democratic short-fallings.

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### **Chapter 1. Introducing the Research**

#### 1.1 Introduction

Deliberative democracy is an alternative to aggregative models of democracy and aims to produce well-reasoned, justified and thoroughly examined decisions through deliberation (Gutmann and Thompson, 2004, Dryzek, 2000). The model has a number of core norms. Arguments ought to be well-reasoned, respectful, and consider the common good. The process should be inclusive of those affected by decisions and involve a range of openminded stakeholders such as citizens, experts, professionals and service users. Due to these specific norms, a particular style of quality deliberation is required of participant's which is distinct from other forms of communication (Dryzek, 2000). Here, deliberation should involve reflective, careful consideration and the weighing up of issues under discussion and it is through this process that fairer outcomes are reached. This style of deliberation is often referred to as type I (Bachtiger, Niemeyer, Neblo, Steenbergen and Steiner, 2009) which includes well-reasoned, rational and justified arguments (Bachtiger et al., 2009). This type of discourse can be associated with micro conceptions of deliberative democracy. These are small, relatively exclusive structured deliberative forums that are focused on decision making (Hendriks, 2006).

It is challenging to institutionalise all the core norms of deliberative democracy as outlined above. This is because it is extremely difficult to involve all individuals affected by decisions in quality deliberation in an equal and inclusive manner (McLaverty, 2014, Chappell, 2008, Parkinson, 2004, Young, 2001). Due to inequalities that exist in society, not all individuals will have the necessary skills to participate in deliberation. Some will face structural barriers as deliberation requires time and others will not have the adequate level of knowledge or

skills to equally participate. As a result, type II deliberation has emerged which includes other forms of communication such as story-telling, rhetoric, personal experience and humour (Bachtiger et al, 2009). This type of discourse can be associated with macro conceptions of deliberative democracy which are flexible, diverse deliberative spaces encompassing the media, associations and networks that are focused on opinion formation and agenda-setting (Hendriks, 2006).

This thesis examines how deliberative democracy can be better institutionalised in organisations through combining micro and macro conceptions of deliberative democracy (Hendriks, 2006). One structure where the model could be institutionalised is in government networks (Dryzek, 2011). This is because they often use deliberation (Papadopoulos, 2012, Dryzek, 2011) to solve complex problems and can embody democratic principles such as representation and participation. Networks are most commonly utilised by governments to make sense of and solve complex, sensitive issues in areas such as healthcare, environment and transport etc. However, these networks often comprise unelected experts and elites (Papadopoulos, 2012, Dryzek, 2011, Hendriks, 2006) and are consequently accused of being unrepresentative, unaccountable and therefore potentially inimical for democracy (Dryzek, 2011).

The National Institute of Health and Clinical Excellence (NICE) is a quasi-autonomous, non-governmental organisation (quango) which is part of a larger health-care governance network. Networks are often criticised for being a private form of government (Greenaway, Salter and Hart, 2007) where unelected individuals make important policy decisions. NICE have responded to such criticisms by basing its decision making processes on principles of deliberative democracy (Daniels, 2008). It has also made attempts to include citizens by developing a Citizen Council (Davies, Wetherell and Barnett, 2006). Consequently, it is an

institution that could potentially combine micro and macro conceptions. NICE has a complex role in developing guidance which is sensitive to ethical, moral, social, medical and economic issues. It is challenging to ensure that guidance is representative of all stakeholders given the diversity of issues that need to be considered. This is particularly the case in public health guidance as these topics span a range of issues such as drug and alcohol use, mental health, weight management, smoking, physical health and pregnancy.

As part of the public health guidance development process in NICE, deliberation could operate at a micro level and be linked to deliberation in the macro sphere. Combining the two could help NICE access a diverse range of participants who might not normally engage in formal modes of deliberation and as a result include different types of discourse in decision making. Furthermore, it would allow NICE to engage with those individuals in their own environment and in less formal structures (i.e. the macro sphere) which could lead to fairer and equal deliberation and outcomes. This would not only address the democratic problems faced by networks but also the primary scale issue with deliberative democracy. This thesis will empirically explore if NICE can combine both micro and macro conceptions of deliberative democracy.

This chapter will outline the purpose and focus of the research by introducing the main bodies of literature that are specific to this research including deliberative democracy, governance networks and empirical research on NICE. While introducing the literature, the main research problem of institutionalising deliberative democracy will be discussed. The main challenge for deliberative democracy relates to scaling-up the model (Parkinson, 2004). It is very difficult for all relevant stakeholders to be included in quality deliberation where issues are weighed up and considered in an equal and fair manner. Deliberative democracy requires a much higher level of civic participation than is currently realised (Chappell, 2008). It takes

time as participants need to be fully informed and they require deliberative skills (Elstub, 2007, Chappell, 2007, Young, 2001, Sanders, 2007, Gutmann et al., 2004). However, due to inequalities in society, resources are unequally distributed and not all individuals have the same skills and resources to participate fairly in the process (McLaverty, 2014).

This research is significant and of importance to our understanding of the relationship between deliberative democracy and governance networks. It provides empirical insights into a quango, a particular type of governance network, which is responsible for making decisions that affect large groups of individuals. Due to the policy influence such governance networks enjoy, there is a need to better understand these bodies from a democratic perspective to ensure they are legitimate, representative and accountable. Here, NICE's decision-making processes are assessed through the lens of deliberative democracy. Most notably this is one of a few studies that considers whether micro and macro conceptions of deliberative democracy can be combined and provides practical ways in which different organisations can do this. Lastly, this research is significant as it links different types of deliberation; type I and II (Bachtiger et al, 2009) with micro and macro approaches to institutionalising deliberative democracy. This link is new and helps to better describe and define governance networks in relation to their structure and style of deliberation. This is needed more than ever as networks operate in all kinds of areas (Hans Klijn and Koppenjan, 2016, Dryzek, 2011). We need indepth knowledge of how important networks, like NICE, operate.

The chapter will briefly discuss how the research was conducted using a mixed method approach including semi-structured interviews and the deliberative quality index (DQI). The chapter will conclude by outlining how the thesis is organised briefly describing the content of subsequent chapters.

#### 1.2 Setting the Scene and the Research Problem

Over the past decade, considerable focus and research has been devoted to the model of deliberative democracy. The model has well developed theoretical and normative roots (Habermas, 1996, Rawls, 1993) and the focus has now shifted to developing empirical evidence to show how the model can be institutionalised as part of good democratic practice (Hendriks, 2016, Elstub and McLaverty, 2014, Steiner, 2012, Thompson, 2008, Hendriks, 2006). Deliberative democracy refers to the idea that legitimate decision making comes from the public deliberation of citizens (Bohman and Regh, 1997). It aims to improve the quality of democracy by strengthening the legitimacy of "democratic procedures and institutions by embracing deliberative elements" (Held, 2006, 238). The core norms of deliberative democracy include reason giving, common good, inclusiveness and open-mindedness. Deliberation ought to focus on well-reasoned arguments that reflect the common-good rather than being based on self-interest. It should be inclusive of all those potentially affected by decisions and participants ought to be open-minded to other opinions and arguments.

Deliberative democracy is theoretically underpinned by Habermas's 'ideal speech situation' (1971) which is a counter-factual idea as it can never be fully implemented in practice.

Consequently, certain core norms need to be relaxed for deliberative democracy to be practiced in the real world. This is often viewed as being problematic as there is a danger of 'concept-stretching' (Halpin and Cintula, 2013, Steiner, 2008, Elstub, 2006).

Over the years, deliberative democracy has evolved through a number of generations (Elstub, 2016). First generation theorists such as Habermas (1996) developed the normative elements of deliberative democracy. Second generation theorists including Dryzek (2000) expanded the definition of deliberation to make it more sensitive to the increasing plurality and complexity in contemporary democracies (Elstub, 2016). Third generation deliberative

democrats' focus on ways in which deliberative democracy can be institutionalised drawing upon empirical analysis of deliberative practices (Elstub, 2016). First and second generations failed to provide practical solutions and ways in which institutions can institutionalise deliberative democracy. This is an empirical study that aims to contribute to the debate on institutionalising deliberative democracy. It does this by building on the work of Hendriks (2006) who conceptualises two different approaches to institutionalising deliberative democracy; micro and macro. At a micro level deliberative democracy operates in structured, contained forums (see Table 1) such as citizen juries, parliaments and deliberative polls which "embody deliberative principles" (Parkinson, 2004, 3). These forums are ideal for deliberation because they are relatively small and have a focused agenda (Hendriks, 2006). Due to the structural conditions of micro conceptions, the style of discourse is reasoned, rational and justified (see Table1). This can be defined as type I deliberation (Bachtiger et al, 2009).

Table 1: Defining micro and macro conceptions of deliberative democracy and type I and II deliberation

Structure of deliberative space	Type of conception	Style of discourse	Type of Deliberation
Well structured Formal Exclusive	Micro	Reasoned Justified Rational	Type I
Flexible Porous Informal Inclusive	Macro	Story-telling Lived experience Humour Emotional discourse	Type II

Indeed, there exist very similar problems with micro conceptions of deliberative democracy and type I deliberation. Micro forums are viewed as being inevitability exclusive (Hendriks, 2006) because they demand a particular style of talk or discourse (type I deliberation). Individuals typically participating in micro forums are those with expertise, resources,

training and knowledge. This implies that only those "willing and capable" (Hendriks, 2006, 493) can participate. The inclusion of all of those affected in micro conceptions of deliberative democracy is therefore difficult to achieve. Type I deliberation and micro conceptions demand a particular style of deliberation that perhaps suits only a privileged few (Young, 2001). The exclusivity of micro conceptions and type I deliberation also links to the scale problem because micro conceptions can only include a limited number and range of people due to the structure and standards required. They are small, self-contained forums where rational, well-reasoned discourse is the common language.

Macro conceptions of deliberative democracy are somewhat different as they have "less structured terms where people engage in open public discourse via associations, social movements, networks and the media" (Hendriks, 2006, 493). Macro conceptions are flexible and informal (see table 1) and ideal spheres for formulating opinion rather than being orientated towards decision making which is more common in micro forums (Habermas, 1996). Participants in macro spheres engage in broader, less structured deliberation to check the preferences and opinions of others to help them consolidate or perhaps change their own opinions. Individuals can enter macro deliberative spaces without being selected or invited to take part and can engage in more than one deliberative space at a time. Participation in macro deliberative spaces is potentially more inclusive and therefore has a role to play in terms of maximising participation and inclusion. Due to the structural conditions of macro conceptions, discourse includes lived experience, humour and emotional discourse (Table 1). This can be defined as type II deliberation (Bachtiger et al, 2009).

Macro conceptions and type II deliberation are also not without their criticisms. Chappell argues that due to scale, arguments found in macro spheres are often "bigoted, badly formulated, factually incorrect and partial" (Chappell, 2010, 300). It is also difficult to

measure macro deliberation as it should occur over time and in different deliberative spaces including the media, face-to-face meetings, in pubs, cafes, associations and networks. Type II deliberation is similarly criticised for being poorly structured and not based on rational evidence (Bachtiger et al, 2009). Both also lack a connection to decision making due to the remoteness of formal structures.

Due to the criticisms of micro and macro conceptions, a combined approach could overcome the limitations of both and enable deliberative democracy to be more fully institutionalised (Hendriks, 2006). Firstly, micro conceptions could overcome their exclusivity problems by accessing more deliberative spaces in the macro sphere allowing better engagement with those participants who frequently use those spheres. Macro deliberative spaces could overcome the lack of decision making abilities by connecting to more formal micro forums and influencing the outcomes of decisions. A combined approach could ultimately help deliberative democracy become a viable model for organisations to implement.

The focus of this research is whether governance networks can institutionalise deliberative democracy by combining these micro and macro approaches. Governance networks are a "relatively stable set of interdependent, but operationally autonomous and negotiating actors focused on joint problem solving" (Hajer and Versteeg, 2005, 341). Networks are a feature in most democracies. This thesis examines governance networks in the United Kingdom (UK) because they have become increasingly prominent in influencing and making policy and "taking over the business of government" (Stoker, 1998, 23). They emerged in the UK due to governmental overload which led to a mismatch between the "demands placed upon government and its ability to respond effectively to those demands" (Self, 1984). As a consequence, there has been a marked shift from government to governance (Rhodes, 2007)

where networks have been increasingly used to unpack complex and sensitive issues which require in-depth expert knowledge and collaborative decision making.

Quasi Autonomous Non-Governmental Organisations (quangos) are part of the governance network structure and are in "no way officially part of government, but are effectively used by government to deliver public policy" (Hogwood, 1995, 207). They play an important role in almost every area of public policy (Greenwood, Pyper and Wilson, 2002) and are established to bring together a range of actors with certain skills and expertise to make decisions (Greenwood et al, 2002). Hunt (1995) has described quangos as a necessary evil in modern governance. Their in-depth expertise and knowledge is a particular strength of quangos and is often what elected officials lack. As they are involved in policy making, quangos should be democratically legitimate, and therefore accountable, representative and inclusive. Quangos however are heavily criticised for failing to meet these democratic norms. For example, participants are unelected and are not directly democratically accountable for their actions (Hunt, 1995). They are often made up of those who have resources, time and skill to participate in deliberation (Haikio, 2007) and have been criticised for excluding newcomers (Papadopoulos, 2012) in the deliberative process.

Quangos, and networks, have become increasingly popular spaces for deliberating complex policy matters (Bogason and Musso, 2005). This deliberation can operate at a micro level in small, structured and formal spaces and at a macro level across a variety of deliberative spaces and outlets such pubs, cafes, associations and through the media. However, due to weaknesses of each conception, quangos could combine both which could improve their outcomes as well as their democratic functioning. This is because they would be connecting to macro deliberative spaces and engaging with individuals who may not normally access formal structures like networks and quangos. This would potentially include a broader

demographic of participant in deliberation such as citizens and service users providing quangos with access to diverse discourse types. Combining micro and macro models also encourages deliberation between individuals operating in each sphere. This is beneficial as individuals can hear opinions, evidence and positions which they may not have previously considered, encouraging reason-giving and potentially the transformation of preference which are both core norms of deliberative democracy.

NICE is a UK quango which was set-up to develop health-care guidance and appraise health technologies. To respond to the democratic failings associated with quangos, NICE have attempted to integrate deliberative methods (Atkins, Smith, Kelly and Michie, 2010) and have adopted deliberative democracy (Daniels, 2008) as a model to develop their guidance. Accordingly, NICE is a relevant case to be explored as it already embodied some deliberative democratic principles in the development of its guidance (Syrett, 2006, Davies, Wetherell and Barnett, 2006, Rawlins, 2005, Dryzek and List, 2003, Gutmann and Thompson, 2002, Daniels, 2000). This research investigates if quangos like NICE can indeed combine micro and macro conceptions of deliberative democracy, which to date has not been explored.

An example of micro deliberative forums in NICE are Public Health Advisory Committees (PHACs) that are responsible for developing public health guidance. These forums can be defined as a micro conception of deliberative democracy because they bring small groups of participants together to deliberate in a relatively fixed, structured and exclusive environment (Hendriks, 2006). In PHAC meetings, a number of committee members are selected and come together to discuss a particular topic and are tasked with formulating guidance by deliberating and discussing evidence. Topics on the agenda include mental health, pregnancy, weight management and addiction. These are important public health issues as they potentially affect a large proportion of society and the debates are usually complex. For

example, NICE was recently tasked with developing public health guidance around needle and syringe provision. One complex debate during the PHAC meetings focused on providing clean injecting equipment for those under 16. This unearthed a number of moral, ethical, medical and financial questions. Some argued that it could encourage children to inject drugs. Others argued that it would give those who already inject drugs access to clean equipment which would prevent the spread of blood borne viruses such as HIV.

PHACs are often made up of topic experts and professionals however, from a deliberative democracy perspective lay citizens and community members should also participate as they can bring a different narrative to the deliberation process which might include lived experience, story-telling and emotional deliberation. This could enrich the deliberative process. PHACs could also be described as an example of epistemic communities because they are "network(s) of professionals with recognised expertise and competence in a particular domain" (Hass, 1992, 3). Due to these characteristics, PHACs are a specifically relevant case study to explore in terms of assessing the quality and style of the deliberation that takes place, and if this is linked to macro deliberation outside formal processes. It is also important to explore how these 'different' types of individuals engage and deliberate in an epistemic community. For example, do they respect their fellow committee members by listening to their arguments and using respectful language? What level of justification do they provide for their own arguments? Do they distort arguments presented to them by their fellow committee members or interrupt their colleagues? Do they use stories and draw upon experience as evidence? These important deliberative democratic questions will be addressed throughout the thesis.

Macro conceptions of deliberative democracy also have a role to play in networks like NICE.

This is because they can potentially link networks to a much broader range of individuals and

discourses. This research will describe the nature and style of macro deliberation occurring outside the formal PHAC process and assess if it is combined with the deliberation in the PHAC meetings. Given that the PHAC meetings have been defined as a micro forum, it is important that both conceptions of deliberative democracy are connected to ensure that a range of discourses (type I and II deliberation) are included in the development of public health guidance. Without this link, the process could be classed as being exclusive, unrepresentative and unaccountable.

To summarise, the issue with deliberative democracy and governance networks is that it is not possible to include all those affected by decision making in quality deliberation in a fair and equal manner. Quangos like NICE, that have adopted deliberative approaches or deliberative democracy as a model, could overcome some of the criticisms they face by combining micro and macro conceptions of deliberative democracy. At the same time, this approach would also help deliberative democracy to address the problems it faces with institutionalisation and scaling-up. This thesis aims to:

- 1. Measure the deliberative quality of NICE PHAC meetings given that it is an example of a quango in a large healthcare network;
- 2. Assess if macro deliberation occurs outside PHAC meetings;
- 3. Assess if macro deliberation is integrated with the micro deliberation; and
- 4. Explore if NICE, and other networks, can integrate the micro and macro deliberative deliberation to overcome the democratic criticisms they face.

#### 1.3 Significance of this Research

The research aims outlined above are significant for a number of reasons. Firstly, NICE are responsible for making judgments that have to take account of scientific and social values and financial priorities. Scientific value judgements are about interpreting the quality and significance of the evidence available; social value judgements relate to society rather than science (NICE, 2008). These values and priorities must be evident in the deliberation of committee members and in the final guidance.

Secondly, their decisions potentially affect large numbers of citizens. Given the scope of the public health topics considered, it is crucial that NICE adopt appropriate measures to ensure democratic legitimacy of their decision making and to ensure outcomes are better and more informed. To be legitimate, the process must meet standards of deliberative democracy and be reasoned, inclusive, representative and respectful of all. This research will explore the PHAC process for these deliberative democratic principles by measuring the deliberative quality. Previous research has not specifically focused on the deliberative quality of governance networks, quangos or any epistemic community or how these structures might combine micro and macro conceptions of deliberative democracy.

Thirdly, whist some NICE processes such as the technology appraisal process (Syrett, 2006) and the Citizen Council (Davies et al, 2006) have been examined from a deliberative democratic perspective, the NICE PHAC processes has not. The public health guidance process should be investigated as the guidance ought to be inclusive and take account of all stakeholders' views. Previous research conducted by Syrett (2006) concluded that NICE lacked accountability as internal decisions were not connected to broader public deliberation. He also defined NICE as a technocratic decision maker characterised by the exercise of expertise rather than one which was deliberative (Syrett, 2006). It is important to investigate

if these democratic failings also apply to the NICE PHAC process as it should be inclusive and connected to broader public deliberation.

Fourthly, the research is significant because it explores the perceptions of committee members involved in PHAC meetings about the guidance development process. In Ursu and Cowl's (2010) research, committee members felt that the beliefs, attitudes, views and opinions of those affected by the guidance were unrepresented. More balance was required in relation to including academic perspectives as well as the lived experience of patients. Committee members felt there was also a domination of medical jargon and scientific evidence. The findings from this study are relevant as the 'exclusionary' use of medical jargon and complex language could limit the meaningful involvement of specific groups in the process as they may struggle to fully understand what was being presented or discussed. A wide range of evidence and discourse should be included in NICE deliberation for the process to be defined as inclusive and representative. The process should also be accessible for a range of individuals. The research will extend this debate by measuring the deliberative quality in PHAC meetings and provide insights into the type of deliberation in PHAC meetings and if there has been any improvement in the process since initial research was conducted in 2010.

Fifthly, this research will contribute to the growing body of empirical evidence on institutionalising and scaling-up deliberative democracy. The research is particularly significant to the debate developed by Hendriks (2006) which recommends a combined micro/macro approach and extends the debate to how this might be practically achieved. This is something which Hendriks (2006) does not particularly address in her theoretical paper. Hendriks (2006) provides insights into how micro and macro conceptions operate, their strengths and weaknesses, and how a combined approach may function. She does not however provide practical ways in which this might be done and which type of organisation

or structure may benefit from the approach. Furthermore, this thesis provides original empirical quantitative and qualitative data which can be used to compare similar networks and epistemic communities against deliberative democracy. It is significant as it links both micro and macro conceptions of deliberative democracy to type I and II deliberation. These have never been formally linked. As will be shown, this will help to better describe and define the deliberation in quangos and networks and their process of decision making. For example, micro/macro conceptions helps define the structure of networks whereas type I and II deliberation helps describe the style of deliberation that takes place in a network. This gives an in-depth description of institutions which are often described as shadowy secretive bodies, operating in the dark (Sorensen and Torfing, 2005). This is important for democracy given the presence of quangos and networks in decision making.

Lastly, the findings and recommendations will be relevant for NICE in relation to their public health guidance development process but also more generally for networks who are interested in institutionalising deliberative democracy, involving stakeholders more broadly and, improving the quality and legitimacy of decision making.

#### 1.4 Overview of Methodology

To conduct this research, a case study approach has been adopted. This involves the close examination of specific cases such as people, topics, issues or programs. Case study research allows for the in-depth exploration of an organisation like NICE and this is vital to meeting the research aims outlined in section 1.2. Two PHAC processes were selected; Implementing Vitamin D Guidance (VD) and the Needle and Syringe Provision (NSP) Guidance review. The PHACs were selected because they had not yet started developing guidance when the

research commenced and it was important that this research could follow at least one PHAC from start to finish to fully understand the whole process.

These two topics were referred to NICE by the Department of Health (DoH). Needle and syringe provisions are currently distributed by local pharmacies and services so that individuals have access to clean injecting equipment. This is a harm reduction method for drug users that potentially prevents the spread of blood borne viruses, encourages injectors to have better injecting technique which prevents damage to veins and discourages drug litter. The PHAC was convened to review the existing guidance on needle/syringe provision. One particularly controversial debate focused on allowing those under 16 years of age to have access to injecting equipment. This was clearly a moral, ethical and medical issue. The moral and ethical issues are that those under 16 are defined as children, should not be using drugs and given that they are children their parents would need to consent to them accessing needles/syringes. The medical issue is that there are under 16's who inject drugs and therefore need clean, sterile injecting equipment to prevent any further medical problems.

Vitamin D was referred to NICE because of a growing body of evidence suggests that vitamin D deficiencies are evident in particular groups of individuals and this required a public policy response. The controversial debates surrounding this guidance were around properly defining at-risk groups (who to include/not include), which groups would have access to supplements and if these supplements should be free and or universal.

A mixed-methods approach was followed adopting both qualitative and quantitative research methods including the deliberative quality index (DQI) and semi-structured interviews. The chosen methodologies for this research were driven by the research objectives. The DQI is a theoretically grounded measurement instrument "that allows researchers to operationalize and

quantify the quality of discourse" (Steenbergen, Bachtiger, Sporndli and Steiner, 2003, 22). The DQI was applied to a number of PHAC recordings in order to measure the deliberative quality in meetings (aim 1). The DQI is a flexible framework and the following variables were applied to a number of speech acts; *nature of speech act* which explores frequency of interruptions, *respect - listening, foul and respectful language* which explores the frequency of respectful listening and foul language used by committee members. *Force of the better argument* measures the frequency of position change amongst committee members and the *level of justification* measures to what extent a speaker gives complete justifications for their positions. *Content of justification* measures the frequency of reference to the common good and stories.

To analyse the data, SPSS was used to obtain frequency data on the number of cases that had a certain characteristic/variable. The frequencies were analysed for each sample and compared with other studies which have used the DQI in a similar way. No studies have been conducted which explore NICE PHAC meetings in the same way.

As a qualitative measure, semi-structured interviews were conducted with a variety of committee members and used to assess if macro deliberation occurs outside PHAC meetings (aim 2) and if macro deliberation is integrated with the micro deliberation (aim 3). The questions were developed using network analysis themes including density, centrality and betweeness. Density tells us about the overall shape of networks whereas centrality is concerned with individuals involved in the deliberation. Betweeness tells us about how deliberation filters to other deliberative spaces and this is important for assessing if micro and macro deliberation are integrated. These concepts are relevant because the interviews aimed to explore the nature of the macro deliberation that occurred outside the formal PHAC meetings and if this deliberation was integrated with the micro deliberation. It was therefore

important to interview those involved in the micro deliberation, explore with them the concept of macro deliberation and who else they engaged with externally in terms of discussing the guidance. The interviews were thematically analysed and quotes were selected and themed under each concept described above.

#### 1.5 Organization of the Thesis

Following this introduction, the thesis is structured in the following way;

Chapter 2 – The challenges and solutions to institutionalising deliberative democracy

This chapter discusses the model of deliberative democracy in detail by outlining the core norms and provides a critique of the model. The chapter discusses the practical challenges associated with institutionalising deliberative democracy which primarily relates to scale, participation, and inclusion (McLaverty, 2014, Chappell, 2008, Parkinson, 2004, Young, 2001). Following from this, the chapter introduces Hendriks (2006) ground breaking research on micro and macro conceptions of deliberative democracy and links Bachtiger et al's (2009) type I and II deliberation to those conceptions. The section concludes by discussing Hendriks (2006) and Bachtiger et al's (2009) combined approach of deliberative democracy which could be applied to overcome the challenges faced with institutionalising deliberative democracy.

The second half of chapter two examines the role of governance networks in combining micro and macro conceptions of deliberative democracy. In doing so, it discusses the emergence of, and reasons for, governance networks in the U.K. The chapter provides a critique of

governance networks outlining their strengths and weaknesses in relation to democracy and concludes by discussing the link that governance networks has with deliberative democracy.

Chapter 3– A NICE Case Study

Chapter three provides an overview of NICE, characterising it as a quango and discussing in more depth the role of quangos. The chapter outlines the key history of NICE from 2002-2015. Since this research is concerned only with Public Health Advisory Committees (PHACs), the chapter will outline the process which PHACs follow to develop guidance. NICE already subscribed to deliberative democratic principles (Syrett, 2006, Rawlins, 2005, Gutmann and Thompson, 2002) and have made significant attempts to include a range of individuals in their decision making processes. The chapter therefore explores this in further detail.

Chapter 4 – Carrying out the Research and Exploring NICE

The purpose of this chapter is to set out the main methodological approaches that were selected to collect and analyse data. It outlines the key research objectives and the methods used, which include semi-structured interviews and the DQI. It discusses and justifies the rationale for conducting case study research and critically evaluates the methods chosen. The chapter will discuss how the PHAC meetings were selected for recording and how committee members were selected as interview participants including sample sizes for the qualitative and quantitative methods. The chapter includes a discussion on how the data was analysed.

Chapter 5 – The Quality of NICE Deliberation in PHAC Meetings

The purpose of the chapter is to discuss the main quantitative statistical findings from the DQI. It presents the NICE PHAC meeting data and also draws upon other studies to shed light on the quality of deliberation occurring in the PHAC meetings. The chapter discusses the key findings that: a) deliberation was typical of micro conceptions of deliberative democracy because it was structured and exclusive aimed at decision making; and b) that the deliberation resembled type I-expert deliberation because it was rational, expert driven and focused on the quality of arguments.

Chapter 6 – Macro Deliberation Occurring Outside PHAC Meetings

Chapter six examined the extent to which macro deliberation was integrated to the micro deliberation. Interviews were conducted with PHAC members from two different NICE PHAC meetings; Implementing Vitamin D guidance and a review of the Needle and Syringe Provision guidance. The data was used to establish: a) how macro deliberation was described by committee members; and b) how it was integrated to the micro deliberation. The chapter discusses the key findings that some instances of macro deliberation occurred and broadly resembled macro/ type II deliberation. However, there were some crucial elements of macro deliberation missing such as deliberation that was inclusive of the wider public sphere including pubs, cafes, networks, associations and the media. The chapter suggests that because of this, deliberation might be described as an extension of the expert deliberation occurring in the micro forum. The chapter concludes by explaining that this deliberation was rarely integrated to the micro deliberation and discusses ways in which NICE, and other networks, might actively encourage this through coupling and using bridge builders.

*Chapter 7 – Concluding the Thesis* 

The purpose of this chapter is to bring together the key messages which have emerged from conducting this research. This chapter will firstly revisit the research problem which focuses on institutionalising deliberative democracy. Including all those affected by decisions in quality deliberation in a fair and equal manner can be a challenge. However, a combined approach (Hendriks, 2006) including micro and macro conceptions of deliberative democracy might overcome these issues. Some governance networks, and more specifically quangos, use deliberative approaches in their decision making processes (Atkins et al, 2010, Daniels, 2008). However, these bodies are often criticised for being elitist and unaccountable. It could therefore be beneficial for quangos to combine micro and macro conceptions to address some of these issues.

Secondly, the chapter will outline the key findings relating to the research aims. The main finding from this research was that there was very little linkage between the NICE PHAC meetings, which were described as micro conceptions of deliberative democracy, and the macro sphere. This is problematic as the PHAC meetings were found to be of high deliberative quality but not necessarily representative or inclusive. A link to the macro sphere is crucial to overcome these democratic issues. The chapter will further discuss the importance of these findings for NICE outlining the recommendations which NICE may wish to adopt to improve their public health guidance development process. Key recommendations include adopting designed coupling (Hendriks, 2016) to formally link the micro and macro spheres. This is a technique used to connect largely disconnected sites to ensure they engage with each other more effectively (Hendriks, 2016, Mansbridge et al, 2012, Papadopoulos, 2012).

Thirdly, the chapter will discuss the theoretical and practical implications for deliberative democracy and governance networks. Micro and macro conceptions are critical for

deliberative democracy in order for it to be institutionalised as it is clear that not one body, like quangos, can practice all the norms. Quangos require a range of deliberative forums and spaces to make legitimate, accountable and representative decisions. Quangos are often described and criticised for being expert led and therefore unrepresentative and this was apparent in NICE. To overcome this, quangos and networks need to be more active in seeking the views and opinions of others and not just those of experts. To do this, they have to be more visible and accessible in a range of deliberative spaces and this may mean hosting deliberative events in different communities, and accessing macro spheres rather than assuming individuals will come to them. Theoretically, the core norms of deliberative democracy need to be relaxed to include other forms of communication. This will help the model overcome the practical challenges it faces with scale, participation and inclusion.

Finally, the chapter will discuss the research limitations and how future research might progress. For example, only two PHAC meetings were explored in this research and therefore the findings cannot be applied to the whole of the organisation. Future research may build on this and explore a range of other PHAC meetings or use this data and compare it with another epistemic community. The chapter will conclude by offering final remarks including some personal reflections and thoughts about conducting this research.

# Chapter 2. The Challenges and Solutions to Institutionalising Deliberative Democracy

#### 2.1 Introduction

Deliberative democracy has developed rapidly from a theoretical statement into a working theory (Chambers, 2003) and has emerged as a credible alternative to other theories of democracy (Warren, 2002). As the theory has matured, it has become more contested because there are many different accounts. For example, deliberative democrats such as Rawls (1993) focus on the importance of public reasoning in deliberation where private interests are eradicated from the process. However, others such as Dryzek (2000) agree that while reasons have to be justified and rational, there should also be a reflective aspect that allows for preference change in deliberation. He describes a more flexible approach to deliberative democracy compared to Rawls (1993) and is a champion of allowing other forms of communication such as humour, emotion, testimony, story-telling and gossip in deliberation (Dryzek, 2000). Most theorists agree however that the aim of deliberative democracy is to improve the quality of democracy by strengthening the legitimacy of "democratic procedures and institutions by embracing deliberative elements" (Held, 2006, 238). The model intends to produce outcomes, decisions and policies which are thoroughly examined and justified through public deliberation, debate and participation and wider inclusion.

The purpose of this chapter is to trace how deliberative democracy has evolved. Firstly, the chapter will discuss the theoretical roots of deliberative democracy by defining the model and outlining the core norms of deliberative democracy. The core norms include reason-giving, common good, inclusiveness and open-mindedness. Deliberation ought to inclusive of all those affected by the decision. It should be based on well-reasoned arguments that focus on the common good and not based on self-interest, encouraging open-mindedness and

reflection. Related to the core norms of deliberative democracy are types of deliberation which have been identified by Bachtiger et al (2009). Type I deliberation is rational, reasoned and justified (Bachtiger et al, 2009). Type II is fluid, flexible and inclusive (Bachtiger et al, 2009). Both types of deliberation will be used to better illustrate the core norms of deliberative democracy.

Secondly, this chapter will address the current and prominent debate focusing on the practical challenges of institutionalising deliberative democracy and solutions to overcome these challenges. The main challenge with deliberative democracy is related to including all individuals affected be decisions in quality, meaningful, fair and equal deliberation (McLaverty, 2014, Chappell, 2008, Parkinson, 2004, Young, 2001). It is impossible to include all those affected by decisions in deliberation that is well-reasoned, justified and considered. This is because taking part in quality deliberation requires a higher level of civic participation than is currently observed. Furthermore, not all individuals can be included equally in quality deliberation due to the inequalities that exist across society. An innovative solution is offered by Hendriks (2006) who argues that these problems can be overcome by combining micro and macro conceptions of deliberative democracy. Micro conceptions of deliberative democracy are small and structured forums which are focused on decision making. Macro conceptions are fluid more flexible deliberative spaces focused on opinion formation. Together they form an integrated deliberative system where discourses from different spheres influence each other. This chapter also argues that due to the structure of micro conceptions of deliberative democracy, type I deliberation is more prominent. In macro conceptions, type II is more prominent. These concepts will be fully defined and described below.

In an attempt to move away from its normative roots, deliberative democracy now requires institutions which can implement the norms of the model. It has been argued that governance networks can promote deliberative democratic principles in their decision making processes (Hendriks, 2016, Dryzek, 2011) thus strengthening their overall legitimacy. This research will explore if networks have the potential to combine micro and macro conceptions of deliberative democracy. This chapter will define and critically assess governance networks and discuss their relationship to deliberative democracy.

#### 2.2 Norms of Deliberative Democracy

Deliberative democracy is theoretically underpinned by Habermas's ideal speech situation (Elster, 1997, Estlund, 1997, Habermas, 1996) which argues that communication should be undistorted and all participants should be free and equal. The ideal speech situation (Habermas, 1971) promotes open participation aimed at rational consensus where all views are aired in an unlimited discourse. Deliberative democracy has a set of core characteristics (table 2) that are consistently agreed by most deliberative democrats. These include: reasongiving, common good, inclusion and open-mindedness (Mansbridge 2009, Elstub 2006, Guttmann and Thompson 2004). Considerable research has been devoted to defining each characteristics and much of the literature discusses these elements. It is important to outline and critique the norms in order to fully understand the theory of deliberative democracy and how then it can be institutionalised. Type I and II deliberation is used to illustrate how the core norms might be realised in practice (see table 2). For example, in type 1 deliberation, reason giving is realised through extensive justification where self-interest is excluded (table 2, line 1, column, c). Reason giving is practically realised in type II deliberation through the inclusion of rationality but also through the inclusion of self-interest (table 2, line 1, column e). The challenges with institutionalising each norm are displayed in column d. For example, the challenge with inclusiveness is the scale issue of practically including all those affected by decisions in the process (table 2, line 2, column d).

#### 2.2.1 Reason Giving

Providing reasons for decisions is the factor that distinguishes deliberative democracy from other approaches to democracy. Habermas states that public and legislative deliberation should rest only on the standards of reason and the better argument with regards to matters of common concern (Habermas, 1962). Publicity is important in relation to reason-giving as it is generally agreed that reasons should be made public. Warren draws attention to the importance of public reason in democracies arguing that it can be created by convincing others that their "normative positions are right" (Warren, 2002, 181). Reasons should be mutually acceptable and accessible (see table 2, line 1, column b).

Both types I and II deliberation accept that reason-giving is important in deliberation. Type I deliberation is very much aligned to the normative idea of deliberative democracy and is aimed at providing extensive justifications and rational reasoning for arguments and positions (table 2, line a, column c). This however can be constraining as participating in deliberation requires having exceptionally well-informed participants which takes time and effort (table 2, line a, column D) and is perhaps unrealistic (Fishkin, 2009, Chappell, 2008). The uniformity around reason giving also prevents particular groups from participating in quality deliberation such as those who are economically or socially disadvantaged. Some groups are better than others at articulating their arguments in rational and reasonable terms (Sanders, 1997). Solutions to such problems have included broadening the deliberative sphere (Morrell 2010, Dryzek 2009, Steiner, 2012) by permitting different forms of communication, such as rhetoric and story-telling (table 2, line a, column e). This is a characteristic of type II deliberation

where other forms of communication are encouraged, particularly around reason-giving. Participants may use stories and personal experience as reasoning rather than using technical or scientific evidence. Type II deliberation attempts to "address a number of the normative and empirical blind spots of the type I program" (Bachtiger et al, 2009, 12).

#### 2.2.2 Common Good

Most deliberative democratic norms are linked. For example, common good is linked with reason giving. Normative versions of deliberative democracy encourage participants to state reasons which are mutually accessible and acceptable aiming to appeal to the common good rather than self-interest. However, differences are evident in relation to type I and II deliberation. Type I deliberation focuses on rational reasoning where participants provide well defined and rational justifications for their reasons. Reasoning is aimed at the common good and therefore self-interest is excluded (see table 2, line 2, column c). However, truly excluding self-interest in reason giving can be very difficult to realise in practice (table 2, line 2, column d). As a result type II deliberation accepts that self-interest and other forms of communication may play a role in reason-giving and more widely in deliberation (table, 2, line 2, column e).

The common good, and in particular self-interest, is a contested area in deliberative democratic theory and as the theory has matured, the view on self-interest has changed.

Debates "continue about whether deliberative democracy is compatible with self-interest and whether deliberative democracy demands consensus between participants" (McLaverty, 2014, 34). Mansbridge et al (2010) adopt a soft approach to self-interest acknowledging that it is difficult to exclude self-interest from deliberation and has argued its inclusion in deliberative democracy because it helps to clarify interests, preferences and reasons. Promoting self-

interest does not necessarily mean participants do not also think more widely about the common interest and when policies are implemented, the real success of these being embraced is dependent on how well they are received. If policy-makers want decisions to be fully implemented on the ground then the deliberative program must be broadened to include self-interest. In good deliberation "people should be encouraged to put their interests on the table" (Steiner, 2012, 102) and all interests should be included. Self-interest in reason giving is a useful form of communication because through exercising self-interest participants can move through a "process of exploration and clarification" of their preferences (Mansbridge et al, 2010, 73). Empirical data supports that position because "when common good arguments are made, they are often not much more than empty words in flowery language" (Steiner, 2012, 103). In practice, it is not realistic to fully exclude self-interest in reasoning. It should be part of the overall deliberative process. Type II deliberation allows for that diversity.

#### 2.2.3 Inclusiveness

Deliberative democracy aims to include all those affected by decisions in deliberation (see table 2, line 3, column b). In line with the normative theory, both type I and II deliberation aim to include all those affected by decisions in the deliberative process. However, this is a relatively unrealistic outlook (McLaverty, 2014) and the "all-affected principle" (Fraser, 2005) could be a significant barrier to effectively institutionalising deliberative democracy (table 2, line 3, column d). Parkinson (2004) admits that no decision making process can involve *all* the people it affects. He further argues that because of this scale issue, deliberative democratic practices cannot deliver legitimate outcomes as the theory intends. Participating in quality deliberation takes time. This means that certain groups could be excluded from the process such as those in paid employment who also have caring responsibilities, those who work unsociable hours and those who feel uncomfortable with the

deliberative democracy "rules of the game" (McLaverty, 2014, 35). Furthermore, when deliberation is scaled up to include all individuals, it is challenging to ensure that all participants are equally included due to power imbalances and inequalities in society (table 2, line 3, column d). This argument also applies when deliberation operates at a micro level as even in small deliberative forums, not all individuals can meaningfully participate at an equal level.

Despite aiming to be as inclusive as possible, type I deliberation has been critiqued as being exclusive (Hendriks, 2006). The formalised style of deliberation ignores the fact that disadvantaged citizens may not have developed the necessary abilities to fully participate in deliberative forums (Angolano, 2012, Young, 2001, Bohman and Rehg, 1997). Type I deliberation follows quite prescriptive, defined standards and as a result can then be accused as being un-fair and exclusive.

Type II deliberation has a much more inclusive approach to deliberation (table 2, line 3, column e) as it encourages participants to use other forms of communication such as story-telling, rhetoric, emotion and personal experience (Bachtiger et al, 2009). This potentially means that more individuals can access and participate in deliberation as a range of communicative styles is permitted across a variety of spheres which can include the media, networks and association. This helps deliberative democracy be a more inclusive decision making model. However, as deliberative democracy has become more flexible and adaptable, by including more styles of communication, the model is also "in danger of losing its core" (Elstub, 2006, 304).

Inclusion is about presence but also voice and although other forms of communication are encouraged in type II deliberation this does not necessarily mean that it is more inclusive and

this needs to be recognised. In his design of democratic innovations, Smith realises that "simply being present does not necessarily mean that citizens will be willing or able to make their views known" (Smith, 2009, 21). Therefore, forums and institutions must consider the way that "institutional norms and expectations can exclude or undermine contributions of certain citizens" (Smith, 2009, 21) as these can effectively prevent some groups from equally engaging in debates even if they are present. For example, using highly complex language that only certain groups of experts understand can be exclusionary. As a result, institutions such as governance networks need to be more proactive in ensuring that participants are given the opportunity and space to voice their opinion regardless of what style of deliberation is encouraged. They can do this by engaging with participants in their own deliberative environment i.e. in communities, and ensure that technical evidence as well as lived experience has a space on the deliberative agenda.

# 2.2.4 Open-mindedness

The final core norm relates to open-mindedness. Authentic deliberation involves "reflection upon preferences induced by communication in a non-coercive fashion" (Dryzek, 2000, 140). In deliberative democracy, participants should be open-minded to other arguments and positions. Preferences should not be fixed and preference change should be encouraged (table 2, line 4, column a). Engaging in deliberation allows participants to develop and learn as it can lead to participants of deliberation changing their initial position through listening to other positions that they may not have considered previously. Deliberation can also have the opposite effect. Being exposed to different or new opinions and arguments can solidify a participant's position as it may encourage participants to develop rational reasons to more strongly support their own position.

There does not appear to be much difference between type I and II in relation to preference change. However, one might argue that there is more opportunity for participants to change their preferences in type II deliberation as it allows for other types of communication (story-telling, experience, rhetoric, gossip) to influence participants.

There are some problems associated with open-mindedness; the main difficulties relate to measuring this cognitive process (table 2, line 4, column c). Goodin and Niemeyer (2003) argue that it is difficult to measure when actual talk ends and deliberation begins. This is discussed further in chapter six, section 6.6. Furthermore preferences are often tentative, unsure and incomplete before and after deliberation (Fishkin, 2009). Therefore significant challenges remain to develop a robust empirical test of this internal process of preference transformation. The DQI goes some way to measuring preference change.

Table 2: Norms of Deliberative Democracy

10	able 2: Norms of Del A: Norm	B: Definition	C: Type I	D: Institutional	E: Type II
	A. Norm	B. Definition	C. Type I	Challenges	E. Type II
1	Reason-giving	Mutually accessible  Mutually acceptable  Encourages broader perspectives	Extensive justification  Coercion excluded  Rational reasoning  Well defined  Refer to public interest /common-good	Relies on well-informed participants	Includes rationality  Includes other forms of communication  Encourages reasonable solutions  Vigorous and creative
2	Common Good	Encourages broader perspectives	Self-interest excluded	Unrealistic outlook of altruism	Self-interest included
3	Inclusiveness	Inclusion of all those affected by decisions  All have access to equal resources	Equal participation  No domination	Scalar problems  Lack of political will  Lack of motivation  Blind to inequalities and power imbalances	Conceptually broader  More inclusive  Accessible  Engaging  Occurs in 'invited spaces'

	A: Norm	B: Definition	C: Type I	D: Institutional Challenges	E: Type II
4	Open- mindedness	Preferences not fixed	Yield to the force of the better argument	Cognitive process – difficult to measure	Same as type I
		Preference change encouraged  Give and take	Willing to listen to other arguments / positions	Unreliable	
		of arguments	Open to change		
			Transformation not aggregation of preference		
			Opportunity to learn and develop		

## 2.3 Justifications

There are three reasons why deliberative democracy is superior. These are the epistemic, prudential and the fair procedure justifications (Elstub, 2006). Deliberative democracy is sophisticated because it enables participants to gain an equally clear and reflective understanding of his ideas and interests (Festenstein, 2002). This is because the act of public deliberation encourages individuals to listen to each other's reasons, gain an understanding of their positions and to successfully structure and articulate their own ideas and preferences. Aggregative systems do not provide the opportunity to do this. This is known as the prudential justification for deliberative democracy (Festenstein, 2002).

The epistemic justification of deliberative democracy maintains that "deliberative democracy is good because it is the best method of producing good decisions" (Elstub, 2006, 7). This is

because, "by generating public reason, it can lead to decisions that are true, well justified or commensurate with justice, needs or the common good" (Elstub, 2006, 7).

Finally, the fair procedure justification is opposed to the epistemic justification. This is because deliberative democracy is based on the premise that there is "no external good by which to judge decisions and that it is fair procedures that enable conflicts over the common good to be debated and resolved" (Elstub, 2006, 8). Outcomes will be fair because they are "derived from fair procedures in which all have been able to participate equally, regardless of what the actual decision is" (Elstub, 2006, 8).

To summarise, there are different types of deliberation. Type I deliberation is very much aligned to the traditional normative version of deliberative democracy whereas type II deliberation encourages a more relaxed version of the model particularly in relation to the styles of communication it permits. It is important to note however that type II deliberation does have a "concrete normative program" that is "open and on-going" (Bachtiger et al, 2009, 14) and should not to be viewed as an inferior alternative to type I deliberation. Type II deliberation, in some ways, aims to make deliberative democracy a more realistic model which can be institutionalised in practice because the goal of type II is s to "identify theoretically promising standards that can be achieved in the real world" (Bachtiger et al, 2009, 14). Type II deliberation seeks to bridge the gap between the idealised versions of deliberative democracy and the empirical problems such as inclusion, space, time, and equality. However, it is difficult to ascertain when the boundaries have been so relaxed that the core norms of deliberative democracy have been lost (Elstub, 2006). Models do need to adapt in order to be sustainable and practical in the real world. Deliberative democracy is an idealised, highly prescriptive model and therefore the boundaries need to be empirically tested before we can ascertain what norms are practically achievable on the ground (Steiner, 2012).

Thus far, this chapter has outlined the core elements of deliberative democracy using type I and II deliberation to better illustrate these norms (table 2). A key challenge for deliberative democracy is institutionalising the model due to scale and with that comes related issues with participation and inclusion. The next section of this chapter will assess these in more depth. Potential solutions will also be discussed, specifically those by Hendriks (2006), who offers two conceptual approaches. By combining micro and macro conceptions of deliberative democracy, the norms of deliberative democracy can be better achieved in practice.

## 2.4 Problems with Implementing Deliberative Democracy

The central theme in this thesis focuses on findings ways in which deliberative democracy can be institutionalised however there are challenges with this which are largely due to including all those affected by decisions in meaningful and quality deliberation. Sceptics have questioned "the practical viability of deliberative democracy... with no hope of being effectively institutionalised" (Curato, Dryzek, Ercan, Hendriks and Niemeyer, 2017, 29). There is clearly a tension between the normative and empirical strands of deliberative democracy. Normative champions including Habermas (1996) and Elster (1998) argue that the core roots of deliberative democracy must be upheld. Empirical champions such as Hendriks (2016), Elstub (2006), Parkinson (2006) and Dryzek (2000) recognise the practical challenges facing deliberative democracy because of the strict habermasian roots and call for a relaxation of the boundaries. Both sides recognise however that it is practically challenging to implement deliberative democracy and struggle to agree on what should or should not be included in the model. Elstub (2007) argues that in order to achieve the normative goals, outlined previously, deliberative democracy now needs devices or institutions to enact it.

Including all those potentially affected by decisions in meaningful deliberation is difficult to achieve due to a range of complexities including social pluralism, inequalities of resources and deliberative skills and the growing need for greater levels of specialism in making decisions. Increased social pluralism makes deliberative democracy unachievable in practice as "it decreases the chance of reaching consensus on a common good and makes the inclusion of all relevant views harder to attain" (Elstub, 2007, 16). Societies have become so widespread and fragmented that decisions are already far removed from citizens due to centralisation and bureaucracy. This challenges the possibility of deliberation with its reliance on participation in discussion (Elstub, 2007).

All these factors of social complexity are "intensified by the growing need for greater levels of specialism in making decisions" (Elstub, 2007, 16). Issues are becoming increasingly complex and decision making requires certain expertise and specialism. This leads to a decline in informed participation, as being informed requires too much time. This also makes lay citizen participation in deliberative democracy more difficult to achieve because state institutions increasingly rely on "experts for policy decisions, which has led to the proliferation of quasi-autonomous, nongovernmental organisations" (Elstub, 2007, 16-17) in the policy process. These bodies are known as quangos and will be discussed in chapter three.

The barriers to implementation make it difficult for deliberative democracy to be realised in practice. However, many diverse and deliberative innovations have been implemented in a variety of ways (Curato et al, 2017). One proposed solution integrates all kinds of deliberation from the micro to the macro (Hendriks, 2006). This combined approach is not necessarily a new solution. In an attempt to resolve the problems with institutionalising deliberative democracy Habermas (1996) suggests a two-track model of democracy where

deliberation takes place on two levels. Broad public deliberation allows for reflection and agenda setting. This deliberation is then transmitted into the more formal spheres such as legislatures, courts and parliaments for the purposes of "will formation" (Habermas, 1996, 307). However, there are a number of issues with the two track model as Habermas (1996) does not pay particular attention to how "resource and deliberative inequalities in the public sphere affect the way in which opinion is transferred to the state" (Hendriks, 2006, 496). For example, power inequalities might prevent some groups of individuals from participating in the deliberation and thus being excluded from the process. Furthermore, Habermas (1996) leaves us wondering how the two levels of deliberation would actually be formally linked and what makes the transfer deliberative (Hendriks, 2006).

A slightly more realistic approach has been suggested by Mansbridge (1999) which includes of a variety of deliberative venues. At one end of the deliberative system is the "informal 'everyday talk' among citizens and social movements and at the other end is the formal decision-making that takes place in public assemblies and parliament" (Hendriks, 2006, 497). This is a more realistic vision as it recognises that deliberation is fluid and not restricted to just one sphere. It cuts across a variety of deliberative venues. However, there are also problems with this approach (Hendriks, 2006). Firstly, Hendriks (2006, 498) argues that Mansbridge (1999) assumes "that the more informal public conversations will work in unison with, and mutually reinforce, the micro deliberation in structured fora". It is often the case that they do no work in unison (Hendriks, 2006).

Due to the limitations of the two track model (Habermas, 1996) and the deliberative systems approach (Mansbridge, 1999), Hendriks (2006) suggests an integrated deliberative system which aims to foster connections between micro and macro forums of deliberation is required. Unlike the two track model, it includes discursive spheres which encompass public venues

and is a "site where public discourse occurs through the exposition and discussion of different viewpoints" (Hendriks, 2006, 499). In Hendriks model, "micro and mixed deliberative arenas are embedded in a broader, informal (macro), discursive context" (Hendriks, 2006, 450). It is different from the two-track model and deliberative system approach because it encourages us to think about the interconnectivity of deliberative sites and who participates in these spheres. Accordingly, Hendriks's (2006) model is more compatible with governance networks.

Networks are becoming increasingly common in the U.K and so Hendriks (2006) argues that we must better understand and consider which stakeholders participate in these networks i.e. experts, citizens, professionals, to ensure they are representative, inclusive and therefore democratically legitimate. Given that networks are often criticised for being exclusive, private decision making bodies, we must also ensure that networks are connected with other sites of deliberation so they are linked to the broader, wider deliberation and therefore accountable and visible.

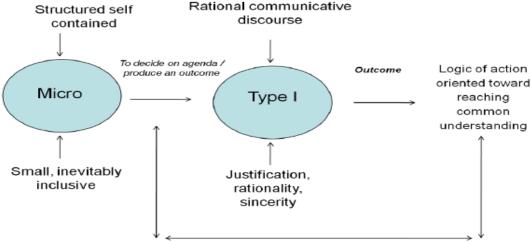
The two conceptual approaches; micro and macro, will now be defined and discussed in greater detail.

#### 2.4.1 Micro Conceptions of Deliberative Democracy

Micro conceptions of deliberative democracy occur in structured fora where "free and equal participants meet to decide on an agenda, reason and argue together and settle on an outcome" (Hendriks, 2006, 492). They can be found in "self-contained forums like citizens' juries, deliberative polls, consensus conferences and parliaments which have said to enact deliberative democratic principles" (Parkinson, 2004).

The communicative ideal for micro accounts of deliberative democracy is that "participants are relatively impartial, willing to listen to each other and committed to reaching a mutual understanding in the view of the collective good" (Hendriks, 2006, 492). This is also quite typical to type I deliberation. To achieve this communicative ideal, participation in micro conceptions of deliberative democracy is small and exclusive (Hendriks, 2006) and as a consequence type I deliberation is more suited to micro conceptions of deliberation. This is illustrated in figure 2.

Figure 2 Micro conceptions of deliberative democracy and type I



Proposing issues for the political agenda occurs in micro conceptions of deliberative democracy where participants can develop binding decisions or recommendations. Topics are defined ahead of meetings and participants are well-defined. Due to this, it is easy to stipulate rules, use moderators and record the deliberation. This makes micro conceptions very structured forums. The characteristics of micro conceptions of deliberative democracy therefore make it easier to implement the normative values of the ideal theory (Chappell, 2010) where type I deliberation is likely to emerge due to these conditions.

Based on this definition, micro conceptions clearly demand a particular type of deliberation that is reasoned and rational. This implies that "only those that are willing and capable of

upholding these deliberative norms should participate" in the micro forum (Hendriks, 2006, 493). This exclusiveness is also a characteristic of type I deliberation. It also means that participation is likely to be small given the standards that are required in order to fully engage in a micro forum. Overall, micro conceptions serve a purpose but are ultimately exclusive where not all "participants may be able to participate in deliberation alike" (Chappell, 2010, 298). Micro conceptions of deliberative democracy are also not suited for the rough and tumble of the everyday discursive events. They are "relatively infrequent, isolated moments of democratic participation" (Chappell, 2010, 299) which rely on the self-selection of participants and resemble the characteristics of the ideal theory more closely than macro conceptions. This conception suffers from many of the problems associated with type I deliberation.

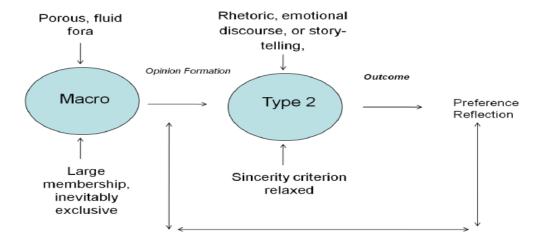
# 2.4.2 Macro Conceptions of Deliberative Democracy

Macro conceptions of deliberative democracy take place in "less structured terms where people engage in open public discourse via associations, social movements, networks and the media" (Hendriks, 2006, 493). The aim of macro conceptions of deliberative democracy differ from the micro as it is orientated around opinion formation rather than decision making (Hendriks, 2006). Deliberation is ongoing, reoccurring and participants belong to different groups. Due to these conditions, type II deliberation is most suited to macro conceptions of deliberative democracy because macro conceptions include the wider public sphere encompassing parliaments to pubs and cafes and back again. This is where a mixture of political behaviour, some which are barely reasoned or deliberative occurs however all contribute significantly to public discourse (Chappell, 2010). It is in macro spaces that ideas and discourses are shaped and challenged (Hendriks, 2006). For this reason, it is essential that macro conceptions of deliberative democracy are identified as part of a wider deliberative

process as it plays a crucial function of linking individuals to more formal processes that are rather exclusive.

Macro conceptions of deliberative democracy encourage contested discourses to emerge involving storytelling, rhetoric and experiences. Figure 2.1 illustrates the characteristics of macro conceptions of deliberative democracy and how type II deliberation is linked.

Figure 2.1: Macro conceptions of deliberative democracy and type II



A criticism of macro conceptions of deliberative democracy is that "public spheres are vulnerable than the more controlled micro conceptions of deliberative democracy" (Habermas, 1996, 308). This is because a vast range of communication styles are permitted in macro conceptions. Consequently, arguments in macro spheres have been accused of being "bigoted, badly formulated, factually incorrect and partial" (Chappell, 2010, 300). This is a similar criticism of type II deliberation as other forms of communication such as emotive discourse are included rather than being focused on rational arguments.

Macro conceptions of deliberative democracy have also been criticised for concept stretching undermining "much of the normative distinctiveness of the original theory" (Chappell, 2010, 1) because it incorporates a flexible approach to communication styles. However, concept

stretching seems inevitable in order for deliberative democracy to be institutionalised in the real world. Different forms of communication cannot be excluded from any democratic model as this potentially excludes certain groups of individuals from participating in democratic decision making. Decision making has to be democratically deliberative and not just of high quality. Eliminating partial and experience-driven discourses excludes an essential account from the process. These are fundamental to informing and creating binding decisions that work on the ground. For this reason, there is certainly a place for macro conceptions of deliberative democracy and type II deliberation. Type II deliberation can work in tandem with micro conceptions if they are integrated properly and institutionalised. This combined approach will be discussed next in section 2.4.3.

#### 2.4.3 A Combined Approach within a Deliberative System

To conceive of deliberative democracy as an entirely micro or macro model is relatively unrealistic (Hendriks, 2006). For example, micro conceptions and type I deliberation are too exclusive and macro conceptions and type II deliberation lack structure and clear links to decision-making. To overcome the downfalls associated with both conceptions of deliberative democracy and with type I and II deliberation, Bachtiger et al (2009) and Hendriks (2006) separately call for the integration of concepts as part of a deliberative system. An integrated system would "celebrate the *multiplicity* of deliberative venues and foster *connections* between these venues" (Hendriks, 2006, 499) and this can allow type I and II deliberation to better influence each other. Micro forums have to be closely connected to the macro discursive setting so that both have any impact on each other (Hendriks, 2006). This could be done through mixed discursive fields which are informal and formal spaces of deliberation (Hendriks, 2006). Examples of mixed discursive fields include deliberative designs, facilitated town meetings and public seminars (Hendriks, 2006). Participants engaging in these fields include a mixture of individual citizens, interest groups

representatives, activists, and experts, the media, government officials and parliamentarians (Hendriks, 2006)

Hendriks (2006) explains that combining micro and macro approaches would allow for a more viable and inclusive deliberative theory as it encourages "diverse actors to come together and cross-fertilise macro and micro conversations" (Hendriks, 2006, 503). Hendriks (2006) model addresses the scale and participation issues that deliberative democracy face. This is because it is inclusive of a wide range of deliberative spheres (micro, macro and mixed), which means that more individuals can potentially participate in deliberation as more spheres are available. The combined approach addresses the inclusion barrier as it is accessible and encourages a variety of deliberation styles to be used due to the different deliberative spaces. This could encourage socially disadvantaged groups to engage in deliberation.

Mixed deliberative spheres are core to Hendriks's deliberative system and play a role in connecting micro and macro conceptions of deliberative democracy. Each deliberative field would have a "predominant form of communication...some would be more structured than others, some more public, some more inclusive, some initiated by the state and others emerging from civil society" (Hendriks, 2006, 500). In a deliberative system, most actors will affiliate with one primary discursive field but importantly are not exclusive. This allows for entry and exit to all discursive fields ensuring that all individuals can enter a deliberative field based on desire rather than on ability or resource. This integrated system is more "porous with respect to alternative or marginalised interests" (Hendriks, 2006, 500).

Mixed spheres encourage diversity and also aim to connect micro and macro deliberative worlds. They encourage participants who might "normally inhabit macro spaces (activists,

interest groups, corporations) and micro venues (parliamentarians, experts, academics, government officials) to come into contact with actors who are typically underrepresented in both (individual citizens) (Hendriks, 2006, 501). Mixed spheres can potentially capture the benefits of both type I and II deliberation without their "respective elitist and populist" downfalls (Hendriks, 2006, 501).

Similarly, Bachtiger, Shikano, Pedrini and Ryser (2009a) argue that a sequential approach is required in relation to finding a middle ground between type I and II deliberation. Type I deliberation has been criticised for being too narrow and ultimately exclusive because of the strict standards. Type II deliberation has been criticised for being too informal and of lower deliberative quality as it includes other styles such as humour, rhetoric and emotional discourse. However, if both type I and II deliberation occurs at different sequences of the decision making process, the limitations of each could be eliminated (Bachtiger et al, 2009a).

This approach encourages deliberation to take place in different sequences where particular forms of communication are encouraged in earlier stages of the communicative processes to balance power inequalities and to encourage social comfort among participants (Bachtiger et al, 2009a). For example, at the early stage of the decision making process, type II deliberation is encouraged to gather experience, stories and personal accounts. Type I plays a role later in the process as this is where deliberation needs to become directive, structured and integrated with type II deliberation.

What is important is that both the sequential approach and an integrated systems approach recognise that there is a need for all forms of deliberation to be included at some point in the process. Not one part of the system or sequence can deliver all the corm norms of deliberative democracy. This is what Mansbridge terms the division of labour (Mansbridge et

al, 2012) and could help make deliberative democracy a more realistic and inclusive model for organisations to implement. One deliberative space may not be able to practice all the norms of deliberative democracy, but if they can access other forums or spaces this could help them better achieve those deliberative democratic standards. A deliberative system includes a range of deliberative spaces which each have a role and function. Mansbridge argues that in a healthy deliberative system "relevant considerations are brought forth from all corners, aired, discussed, and appropriately weighed" (Mansbridge et al, 2012, 43). This division of labour aims to ensure that parts of the system can enact deliberative democratic norms rather than expecting one part to enact them all.

Recently, Chambers (2017) discussed a systems approach in order to balance epistemic quality and citizen participation as often there are challenges with achieving both. She argues that a deliberative system "splits the multiple functions of deliberation and identifies different arenas and contexts in which different elements of deliberation predominate" (Chambers, 2017, 268). This means that micro and macro conceptions of deliberation should operate as part of a good deliberative system. In a deliberative system, not all "citizens need to be equally knowledgeable; not every political conversation needs to achieve rational discourse" (Chambers, 2017, 268). Experts can play a large role in a deliberative system as long as "citizens are also able to exercise some form of democratic oversight" (Chambers, 2017, 268). Chambers' (2017) position offers a more realistic view of deliberative democracy as it splits the division of labour across different deliberative arenas; micro and macro. It also addresses the issues with scale, participation and inclusion. This is because it accepts that not all citizens need to have the same skill or level of knowledge. This is important as inequalities are unavoidable in societies. Chambers (2017) argues that experts (which are necessary to provide expertise and information) still play a role in a system however they should be challenged and scrutinised by citizens. This is central to democratic legitimacy as experts are

not always right and neither are citizens. This process allows for the give and take of reasons, challenge and scrutiny of both types of participants and the evidence they bring to decision making processes. Finally, outcomes can be achieved through other types of deliberation rather than through rational discourse. This is vital for inclusion as participants often draw upon a range of discourse such as lived experience and not just rational discourse.

This division of labour however can still favour elites (Chambers, 2017) because it allows for epistemic elites to "come up with the agendas, ideas, and policy positions and democratic publics ratify or repudiate the agendas but do not generate or really engage with them" (Chambers, 2017, 265). However, this can be avoided if parts of the deliberative system are better connected. This can be achieved through combining micro and macro conceptions of deliberative democracy. Chambers (2017) somewhat alludes to this through the process of feedback loops where elites "need to be responsive to the problems, concerns, and interests of citizens and citizens need to be responsive to the information and persuasive arguments presented by elites" (Chambers, 2017, 272). This could be achieved in practice if micro and macro sites are formally connected and linked so feedback can meaningfully occur between deliberative sites

A deliberative system approach clearly "remains a work in progress" (Hendriks, 2016, 43) however it ensures that deliberation is divided among different sites and actors where both type I and II deliberation can be encouraged to develop. Crucially, all parts of the system (micro and macro) need to be connected or linked appropriately. One strategy to do this is through coupling deliberative sites (Hendriks, 2016, Papadopoulos, 2012) which ensures deliberative sites are connected through tight, loose and formal links. Networks, which are traditionally dominated by topic experts but largely deliberative forums, can couple with

wider public spheres where a range of different types of individuals can set agendas, come up with ideas and policy positions.

Despite Hendriks (2006) arguing that sites of deliberation would be theoretically connected through mixed discursive spheres, it is not clear how this could be practically achieved and how particular institutions would achieve this link. This is the main criticism with her solution. To address this gap, this thesis aims to empirically explore through case study research how macro sites might be practically combined with formal micro sites. Governance networks have been selected to carry out the empirical test.

Governance networks have been selected as a potential institution for several reasons. Firstly, governance networks promote and embody deliberative democratic principles and some use deliberative methods to formulate decisions (Calmar-Andersen and Loftager, 2014, Klijn and Skelcher, 2008, Dryzek, 2011). Consequently, they are a suitable case to explore if they could potentially combine micro and macro conceptions of deliberative democracy. Hendriks (2008) alludes to governance networks being suitable institutions and offers strategies to make governance networks more inclusive by connecting network structures to more direct forms of citizen engagement. She further suggests that networks need to encourage discursive inclusion through ensuring that discourses from the public domain (macro sphere) can effectively enter policy deliberations (micro sphere). Governance networks may have the potential to combine micro and macro conceptions of deliberative democracy which could help overcome some democratic issues they face such as accountability and representation and at the same time help deliberative democracy overcome the problems it faces with institutionalisation (scale, participation and inclusion). Combining micro and macro conceptions may be a win-win for both governance networks and deliberative democracy. The last section of this chapter will discuss in detail governance networks.

#### 2.5 Emergence of Governance Networks

With the move from government to governance (Rhodes, 2007), networks have become increasingly numerous in a complex society. Networks emerged as governments "seldom control all the resources required to provide adequate and effective responses to social problems in terms of knowledge, organisation, or even trust and legitimacy" (Papadopoulos, 2012, 132). Networks help solve complex, often transnational policy problems. They are used to unpack large complex problems into manageable, non-political issues. For example networks are often used in; a) the organisation of integrated health care and social services which requires cooperation between different partners; b) in processes of policy implementation or law enforcement; c) managing large scale accidents or large scale social disturbances and their aftermath; and in d) complex decision making processes in relation to realizing, operating, and maintaining public infrastructural works (Hans Klijn and Koppenjan, 2016). These are all areas which require in-depth knowledge, expertise and cooperation between stakeholders. Networks are used by government to bring those with expertise and specialised knowledge to the table as they lack this level of expertise. Due to increasing specialisation and the growth of society, governments need to draw upon networks to solve complex and sensitive issues. Complex policy problems also require a "shift from a more traditional top-down way of problem solving to a more horizontal cooperative approach, which is often referred to as the shift from government to governance" (Hans Klijn et al, 2016, 4). This encourages collaboration which, as mentioned above, is required to solve complex issues. As a result, networks are an important aspect of governance because they play an integral role in an ever changing and complex system.

2.6 Defining Governance Networks

Defining networks can be problematic. This is because not all networks fit neatly into one

definition. For example, Rhodes defines governance networks as self-arranging organisations

which need to exchange resources (money, information, knowledge, expertise) to achieve

their outcomes (Rhodes, 1997). Hans Klijn et al (2016) define them as "more or less stable

patterns of social relations between mutually dependent actors, which cluster around policy

problems, a policy programme, and/or a set of resources and which are formed, maintained,

and changed through one or more series of interactions" (Hans Klijn et al, 2016, 11).

Despite varying definitions, most networks have common characteristics. For example, they

have members from a variety of backgrounds. Those members are autonomous but are

interdependent due to the resources each member has i.e. specific expertise or information.

For this reason, relationships in networks can be complex and power struggles can be evident

(Hans Klijn et al, 2016). The common characteristics of networks are further described in

Table 2.1.

Table 2.1: Common Characteristics of Networks

Networks are characterized by complex policy problems that cannot be solved by one

actor alone, but require the collective actions of several actors

Networks have relatively high interdependencies between actors because resources

necessary to solve problems are owned by different actors

These interdependencies cause a high degree of strategic complexity and an unpredictable course of (inter)actions as actions of one actor affect the interests and

strategies of other actors

Networks have complex interactions because each of the actors is autonomous and

has its own perception of problems, solutions, and strategies

Network interactions show some durability over time

Source: Hans Klijn et al (2016), p160

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Relationships in networks are conceived not as hierarchies but where private and public sectors are bridged through collaboration (Tuohy, 2003). They are very diverse and membership consists of a constellation of "interdependent but autonomous actors from public, private, and societal sectors" (Hendriks, 2009, 690). Networks also vary in size and in their organisational structure which alters their relationship with the political sphere and the state.

The term governance and networks are commonly articulated together and the order of these concepts is of importance when defining particular networks. The term governance network is concerned with the "articulation, resolution and realization of public values in society" (Klijn and Skelcher, 2007, 587). It is associated with new "hybrid organisational forms that play a major role in shaping and delivering public policy to citizens and communities, including quasi-governmental agencies, public-private partnerships and multiple organisational boards" (Klijn et al, 2007, 588). The alternative and more commonly articulated order network governance is a "higher level concept associated with a particular mode of societal organisation, which is usually contrasted with market and hierarchy" (Klijn et al, 2007, 587). The two terms highlight the different relationships that networks can have in the political sphere. Network governance is related to the how networks organise and associated to with markets and the economy. On the other hand, governance networks are related with new systems for public policy deliberation, decisions and implementation (Hans-Klijn et al, 2016). They aim to solve complex policy issues and due to the complexity of decision making require horizontal and cooperative approaches rather than traditional topdown ones. This research is concerned only with governance networks, their role in institutionalising deliberative democracy and their ability to combine micro and macro conceptions of deliberative democracy.

#### 2.7 Networks in the U.K

Networks emerged in the U.K to deal with "wicked problems" (Rittel and Webber, 1973) which refer to problematic societal issues where there is "no obvious solution, many individuals and organisations are necessarily involved, there is disagreement between stakeholders and where desired behaviour changes are part of the solution" (Ferlie, Fitzgerald, McGivern, Dopson and Bennett, 2011, 307). These problems demand a "broad systemic response, working across boundaries and engaging citizens and stakeholders in co-producing policy-making and implementation" (Ferlie et al, 2011, 307). This is where networks play a role.

In the U.K, networks have been identified as early as 1901(Flinders, 2004) however since 1997 a large number of networks emerged, and in particular quangos, as a core element of the Labour government strategy in a response to "government overload" (Davies, 2007, 49). This is essentially the mismatch between the demands placed upon government and its ability to respond effectively to those demands (Self, 1984). Networks appealed to the government of the time as they offered independence and control while at the same time marrying the public and private sectors" (Flinders 2004, 892) encouraging effective responses to those "wicked problems" (Ferlie et al, 2011). Networks were used by the Labour government to "foster public confidence in the operation of democracy in general" (Flinders, 2004, 892) by opening up dialogue and adopting a "far wider and more inclusive approach" to distributed public governance (Flinders, 2004, 887) and at this time were most pertinent in the field of healthcare (Davies, 2007). A more inclusive approach meant brining a range of participants together such as professionals, experts and lay citizens together to deliberate on particular complex societal issues. As such, a network society arrived in the U.K marking a shift from government to governance (Rhodes, 1997).

In 2010, the Cabinet Office listed a total of 742 operational quangos in England alone (BBC, 2010) and they operate as part of the network structure. Quangos are commonly defined as "public bodies operating at arm's-length to ministers" (Flinders and Skelcher, 2012, 327). One well known quango is NICE who are responsible for developing health and social care guidance as well as appraising health technologies such as new drugs. They are therefore tasked with making complex moral, social, ethical and financial decisions and as a result are an interesting case study to explore. They ought to be inclusive, representative, accountable and legitimate. The role of quangos and in particular, NICE, will be discussed in more depth in chapter four.

# 2.8 Critique of Governance Networks

Networks that base decision making on deliberation have particular strengths as they provide opportunities for different actors with a range of expertise and knowledge to engage in dialogue with each other. This means that knowledge and resources can be better utilised (Hendriks, 2009) because of the plurality of participants. Furthermore, the exchange of dialogue can help influence or inform other actors of different arguments and views on complex issues which can lead to rational outcomes.

However, some networks have been criticised for having no agreed norms, procedures or constitution to follow and consequently suffer from "institutional ambiguity" (Hajer and Versteeg, 2005, 341). This can make it difficult to define and identify these networks as they have the power to mobilize outside set boundaries with no agreed norms or procedures. This ambiguity poses a legitimacy problem because there are no set rules to determine what

constitutes a legitimate decision making process. Networks can descriptively claim to make legitimate outcomes (Hendriks, 2009) due to this ambiguity.

The organisational flexibility and speed of networks is much more efficient than the government and this is an advantage when dealing with complex, transnational policy problems (Flinders, 2004). However, this can also be problematic. Organisational flexibility means that networks are unaccountable to government due to separation from parent ministries. With a lack of governmental and citizen accountability, the democratic deficit becomes larger.

Policy networks who base their decision making on bargaining and exchange potentially question the constitutional norms and concepts of representative democracy (Dryzek, 2002) including legitimacy, representation and accountability. Such networks have been criticised for being a private form of government (Greenaway, Salter and Hart, 2007) where a range of unelected actors make important and complex decisions. This is essentially the private management of public affairs. These officials are often "traditional elites, especially business elites" (Dryzek, 2011, 119) who have the time, experience, and leadership skills (Dryzek, 2011) that perhaps other groups of individuals lack such as those from lower socio-economic backgrounds. This notion of private government makes accountability even more difficult to achieve. Dryzek argues that this form of government makes "power invisible" (Dryzek, 2011, 120) and decision making unaccountable.

In western democracies, networks are seen as necessary as citizens concerns need to be represented in between elections. Governance networks are viewed "as a means of enhancing democratic legitimacy by facilitating political participation and influence on the output side of the political system (Fung and Wright 2001). In terms of representation and accountability,

participants in networks could often be in "much closer contact with the clientele of their programs than most politicians" (Hunold, 2001, 157). Decisions made through networks should be representative if they are engaging in a range of deliberative spheres. Networks can potentially help solve the problem representative democracy faces; representation for all those affected providing they are inclusive of a those voices. Networks can "be viewed as a potential source of democratic legitimacy, renewal and empowerment because they can engage affected stakeholders and citizens in the governing process" (Hendriks and Boswell, 2015, 4).

Governance networks come with many democratic limitations and challenge the central idea of democratic decision making, however they can still complement democracy (Dryzek, 2011). This is because they aim to include a range of individuals and their voices into the complex process of decision making. The consequence of this is that decisions which are reached are better informed, evidenced and justified when compared to decisions that are the result of aggregation. Networks can complement democracies as they give stakeholders the ability to influence the outcome of decisions and guidance. They do this through encouraging participants to discuss evidence and experiences. Given that they can complement democracy and are mainly deliberative (Dryzek, 2011), networks may well be viable institutions which can effectively combine micro and macro conceptions. This would potentially address the democratic failings they face and at the same time help deliberative democracy overcome the problems of institutionalisation.

## 2.9 Deliberative Democracy and Governance Networks

The growth of networks has been driven by the democratic accountability agenda (Papadopoulos, 2012) which aimed to make policy making "more accessible, accountable and

transparent by ensuring direct participation or representation of citizens in administrative affairs" (Papadopoulos, 2012, 129). As a result, some networks embody the principles of deliberative democracy (Hendriks and Boswell, 2015, Dryzek, 2011) and use deliberative methods (Papadopoulos, 2012, Dryzek, 2011) rather than aggregation to determine policy issues. Networks have become a "space for deliberation and negotiation regarding public policy" (Bogason and Musso, 2005, 3). Deliberation in networks is a tool for managing complex issues and when it involves a range of actors, it helps to "cope better with problem complexity because it allows the grounding of decisions on more accurate knowledge" (Papadopoulos, 2012, 127). For example "through reason giving and the convincing force of justification, actors may be persuaded to change their preference and include considerations they initially ignored" (Papadopoulos, 2012, 132).

Dryzek (2011) argues that networks can be evaluated in deliberative terms and despite their anti-democratic potential and being largely composed of elites, they can be deliberative and democratic. Networks have more than one centre, particularly in relation to power, and their source of coordination is language (Dryzek, 2011). As a result, these networks have more "potential for promoting dialogue compared to their more hierarchical alternatives" (Bevir, 2006, cited by Dryzek, 2011, 122). This dialogue is at the heart of deliberative democracy. Dryzek further argues that to "exert influence an actor has to persuade others in the network" (Dryzek, 2011, 122). This principle is also fundamental to deliberative democracy; one of the core norms is the transformation of preference (see section 2.2.4). Individuals must present arguments that others would find acceptable and reasoned. Networks therefore need to subscribe to deliberative standards. Gutmann and Thompson (1996) argue that networks can be defined as deliberatively democratic if communication is public, that those who engage in a network can be held accountable for what they say and do and if arguments are underpinned by reciprocity. Similarly, Dryzek (2000) suggests that communication in networks can pass

the deliberative test if deliberation is capable of inducing reflection, are non-coercive and able to connect any particular statement of particular experience, like personal stories, to some more general point or principle.

Governance network theorists such as Jessop (2000) and Rhodes (2000) argue that governance networks provide a supplement to representative democracy because they provide an extra channel of influence to those who are intensely affected by certain decisions. That is only the case however if those affected by decisions are included in the network and they are democratic (Sorensen and Torfing, 2009).

Some governance networks, particularly in fields relating to health-care and the environment, have evidence of promoting and adopting deliberative democratic principles and practices (Dryzek, 2011, Atkins et al, 2010). Due to this established link, networks may be suitable structures to help deliberative democracy adapt to the primary issue with involving all affected by decisions in the deliberative process in a fair and equal way. They can do this by combining micro and macro conceptions of deliberative democracy. Combining both conceptions overcomes the limitations of each resulting in a real-world version of the model. For example, macro sites can help micro sites be less exclusive by introducing other forms of communication to the process such as stories and opinions. The potential for governance networks to do this will be explored throughout the thesis.

In principle, networks may be seen as a promising step towards a more horizontal and open process of decision making (Papadopoulos, 2012,). However, governance networks have been criticised from a deliberative democratic perspective. The "democratic potentials of network governance are seldom envisaged" (Sorensen et al, 2009, 243) therefore, there is a need for mechanisms to ensure liberty and accountability (Bogason et al, 2005).

Networks can be deliberative but also largely undemocratic because they are "insufficiently representative" (Papadopoulos, 2012, 129). Some are often criticised for being elitist, technocratic (Hendriks et al, 2015) forums that are dominated by experts (Dryzek, 2011). Networks are an example of "governance with some of the people" because they are dominated by the same type of participant and this cannot make up for a "lack of government by and of the people" (Schmidt, 2006, cited by Papadopoulos, 2012, 134).

This argument is also presented by Dryzek (2011) who argues that it is simply not enough that networks are deliberative. They also must adhere to democratic principles (Dryzek, 2011). This is potentially problematic. Core to deliberative democracy is that for decisions to be legitimate, all those affected by the decision have the "right, opportunity, and capacity to participate in consequential deliberation concerning its content" (Dryzek, 2011, 122). This links to the scale problem outlined by Parkinson (2004). It would be impossible for networks to apply this principle to their decision making processes.

Participants of networks tend to be self-selecting because of connections, resources, expertise and skill (Haikio, 2007) and may "erect barriers against the participation of newcomers" (Papadopoulos, 2012, 133). Due to this, networks can be exceptionally exclusive and "privilege scientific evidence and professional experience over other sources of knowledge such as local or cultural custom, or personal experience" (Hendriks et al, 2015, 7). To be included in some networks "actors must possess resources that are unevenly distributed" (Papadopoulos, 2012, 133) such as high levels of professionalism. Despite attempting to include a range of voices in the decision making process, networks may still be unrepresentative because participants in networks are selected mainly "due to the "the resources they possess, which are necessary for 'steering'" (Papadopoulos, 2012, 135)

Consequently, networks may be made up of the same type of individual based on the resources they have access to rather than diverse groups.

Networks also appear to violate the deliberative norm of publicity (Hendriks et al, 2015) and present "obvious challenges to democracy and democratic theory" (Dryzek, 2010, 119). They typically operate behind closed doors preventing outside scrutiny of their processes.

Papadopoulos argues that they are not as transparent and public as they ought to be as "lay citizens do not know much about governance networks" (Papadopoulos, 2012, 135). This is particularly problematic because if citizens do not know about them, how can they gain access and influence the decisions they make which ultimately may affect them?

Lay citizens, experts and professionals are meant to deliberate together and solve complex problems in governance networks however the inclusion of lay citizens may just simply be symbolic politics (Papadopoulos, 2012). For example, Papadopoulos argues that "deliberation is valued, but only in narrow elitist circles" (Papadopoulos, 2012, 146). As a result, the extent to which citizens can really influence decisions is uncertain. He argues the trend in deliberation that once favoured plurality has turned towards "deliberative elitism" (Papadopoulos, 2012, 146) and is a sign that decision makers continue to find that deliberation cannot be reconciled with equal participation" (Mutz, 2006, cited by Papadopoulos, 2012, 146). In order to overcome this he argues that deliberation needs to be "less dependent on the needs of power holders" (Papadopoulos, 2012, 147).

Some of the democratic issues that networks face however can be solved. Dryzek (2011) argues that networks should be evaluated and interpreted as part of a deliberative system. To be part of the system, networks may need to access a broader range of discourses and participants in public spaces. They can do this by tapping into different deliberative spaces

and connecting to macro spaces. This could help alleviate some of these issues faced by governance networks such as representation, legitimacy and accountability. Indeed, Papadopoulos (2012) alludes to this idea of connecting to other spaces via coupling. This strategy is developed more in this thesis as a potential solution for NICE. If networks are viewed and accepted as being part of a wider deliberative system, the democratic issues may not be so problematic. This is because networks could connect and integrate with other deliberative spaces in the wider public sphere, access a range of voices and encourage individuals to participate in deliberation that might not normally engage in such processes.

There is clearly is a win-win situation developing for governance networks and deliberative democracy. Given that some networks already embody and promote deliberative democracy (Dryzek, 2011, Atkins et al, 2010) they may be viable institutions which can combine micro and macro conceptions of deliberative democracy. This could help networks produce well-reasoned and justified decisions. Combining micro and macro spheres also helps them address some of the issues they face with representation, accountability and representation. This surely benefits governance networks while at the same time help deliberative democracy to become a more viable and inclusive model for organisations to institutionalise.

## 2.10 Conclusion

This chapter has outlined the theory of deliberative democracy by drawing upon type I and type II deliberation to better illustrate the core norms of deliberative democracy. There are clear challenges in institutionalising the ideal model of deliberative democracy. It is impossible to include all those affected by decision making in a quality deliberation. This is because participating in quality deliberation takes time (Gutmann et al, 2004), skill and knowledge (Young, 2001). However, this chapter has identified a potential solution to this

problem. Hendriks (2006) recognises that deliberative democracy can and does operate at a micro and macro level where norms of the model are practiced in different forums and spaces. Due to the structure of micro and macro conceptions, different types of deliberation are evident; type I in micro and type II in macro. There are however downfalls with micro and macro conceptions of deliberative democracy. Micro conceptions of deliberative democracy are too formal and rather exclusive. Macro conceptions are criticised for being too informal with little structure or standards. A combined approach is required to address these issues. Macro conceptions could influence micro conceptions to overcome the issues they face with exclusivity and micro conceptions could influence macro conceptions to overcome the issues they face with structure by allowing micro discourses to influence decision making. Hendriks (2006) offers some theoretical ways in which these can be combined through mixed spheres however, her theoretical paper does not provide ways in which organisations / structures might practically achieve a combined approach. This research aims to address this through exploring if governance networks can practically combine micro and macro conceptions.

Networks may be viable structures to combine approaches as some embody and promote deliberative democracy in their decision making processes (Atkins et al, 2010). Networks can promote principles of deliberative democracy through including a range of stakeholders from different backgrounds in the process such as citizens, professionals and experts and they are fundamentally deliberative (Dryzek, 2011). Governance networks do have a number of strengths. They bring topic experts into complex decision making processes and help unpack sensitive and complex issues. Elected members simply do not have the expertise and level of knowledge that experts have on these issues. However, they do suffer from democratic legitimacy problems as those experts are unelected and accountability mechanisms are largely absent. They often operate behind closed doors and have been defined as being "unstable and

opaque" (Sorensen et al, 2009, 236). They also cannot practically include all those affected by decisions in their process. Due to these problems, networks may benefit from combining micro and macro conceptions of deliberative democracy. Macro conceptions of deliberative democracy comprise a wide range of individuals, some of which may never have typically engaged in a formal network. Through connecting to these spaces, this allows networks to engage better with other forms of deliberation such as stories, experiences and opinions. This may bring a different type of information / evidence to the more formal micro spheres. Micro conceptions would help participants in macro spheres access and utilise the expertise and the knowledge they need to formulate opinions and make informed decisions.

# **Chapter 3. A NICE Case Study**

#### 3.1 Introduction

NICE is a quango which operates in a very large health care network. They embody deliberative democratic principles (Daniels, 2008) and use deliberative methods to formulate their guidance. This makes the organisation an ideal case study to assess if quangos can combine micro and macro conceptions of deliberative democracy. NICE are responsible for developing national guidance and advice to improve health and social care in England and Wales. They are of interest given their remit is so vast and will consequently affect many individuals. How they include and consider all those individuals in their discourse is of particular interest.

Firstly, given that NICE are a quango, this chapter will define and discuss the role of quangos and outline the reasons why governments use them. It will also assess their strengths and weaknesses. Quangos are a necessary part of increasingly complex societies as they bring experts to the table to help solve complex problems (Elstub, 2007) and play a vital role in governance, particularly in managing politically sensitive issues (Payne and Skeltcher, 1997, Hunt, 1995). Consequently, it is important that they are democratically sound, accountable and legitimate because the decisions they make impact on a range of individuals. However, they have been criticised for being particularly undemocratic bodies (Skelcher, 1998) that make important decisions behind closed doors.

Secondly, this chapter discuss NICE's responsibilities and key historical developments. In 2005, public health was introduced to NICE's remit and the first guidance published in 2006. NICE already embody and promote some deliberative democratic standards (Gutmann and

Thompson, 2002). They have based their decision making model explicitly on deliberative democracy (Daniels, 2008). NICE have aimed to respond to numerous criticisms associated with quangos, and more broadly networks. NICE developed a Citizen Council (Davies et al, 2006) which brings lay citizens into the deliberative process and it subscribes to procedural principles (NICE, 2008) which link to the norms of deliberative democracy. They also engage a range of stakeholders in their decision making process (Elstub, 2008). The chapter will discuss how NICE has subscribed to the norms of deliberative democracy by outlining the procedural principles such as transparency in more detail.

NICE is an exceptionally large organisation and it would not be feasible to investigate the whole body. This thesis is specifically focused on the development of public health guidance and the role of the Public Health Advisory Committee (PHAC) meetings. As a result of the inclusion of public health, it was recognised that new approaches and different evidence would need to be considered given that public health spanned such varied topics and potentially affected more individuals (Kelly, Morgan, Ellis, Younger, Huntley and Swann, 2010). Public health guidance would need to include technical and scientific evidence while at the same time social value judgements. Social value judgements relate to society rather than science while scientific value judgements are about interpreting the quality and significance of the available evidence (NICE, 2008). This essentially means that a range of evidence (type II deliberation) would need to be considered in meetings and not just scientific and technical evidence (type I). This is why the development of public health guidance is of particular interest as a mixture of evidence should be used by the committee members responsible for developing guidance. The chapter outlines the public health guidance development process and role of PHACs in this process.

# 3.2 Defining Quangos

Quango is taken to stand for quasi-autonomous non-governmental organisation (Hogwood, 1995) and is referred to organisations which are in "no way officially part of government, but are effectively used by government to deliver public policy" (Hogwood, 1995, 207). Every different quango will have their own set of production rights which are partly controlled by the minister of a parent department of the government. For NICE, this is the Department of Health (DoH). Quangos have autonomy over their managerial structure and operation because they are responsible for their own input, output and procedures. As Thiel notes, ministers "remain accountable for policy matters, the choice of quango and supervision of quangos" (Thiel, 2004, 178). Quangos can also be characterised as "organisations which spend public money and fulfil public functions but exist with some degree of independence from politicians" (Grieve, Flinders and Thiel, 1999, 136). It is important to note that the majority of definitions characterise quangos as being largely independent from any government.

There are four types of quango: "contract agencies, public bodies, voluntary or charity organisations, and state-owned enterprises" (Thiel, 2004, 176). The National Institute of Health and Clinical Excellence (NICE) can be defined as a quango within a governance network. This is because NICE plays a role in shaping public policy through producing recommendations and guidance. Specifically, NICE is an example of a contract agency quango as it is quasi-autonomous working with the DoH. Their tasks are publically driven and they are located in the public domain (Grieve et al, 1999, 142).

Quangos are essential in modern governance as they can provide functional expertise (Weir, 1996) in complex topic areas such as the environment and healthcare by selecting topic experts to engage in deliberation and decision making. Quangos are effective in implementing certain policy areas, as they are at a 'distance' from the relevant, but inevitably

bureaucratic government departments and local authorities (Harden and Marquand, 1997, 10-11). However, quangos have been criticised for suffering from legitimacy and accountability problems. Members of quangos are appointed rather than elected (Flinders, 1999). They are often dominated by professionals and technical experts (Weir, 1996) and are inaccessible to the public. For these reasons, they could be defined as an example of a micro conception of deliberative democracy where membership is relatively exclusive, formal and structured (Hendriks, 2006). Quangos need to respond to these criticisms and one way of doing this might be through linking with macro conceptions of deliberative democracy where membership is more inclusive, fluid and informal. This would allow quangos to potentially include more discourses in their decision making processes, be more accessible in a range of deliberative spaces and widen their participation to more than just professionals and technical experts.

#### 3.3 Government Utilisation

With the development of a network society, a large number of quangos emerged as a response to government overload. Societies have become increasingly complex and policies require specialist expertise which ministers may lack. Through using quangos, policy making and the delivery of service can be more efficient as they advise ministers on matters requiring specific or technical expertise (Hunt, 1995). Governments can receive high quality advice and guidance from acknowledged experts in complex fields and therefore quangos are part of a necessary strategy in response to the major problems of complex modern governance.

Quangos are also flexible and are particularly useful at "forming and organising information as they specialise in certain areas which are of particular relevance to their members and this provides counter-knowledge to other experts (Elstub, 2008).

Quangos are most often used for the management of political sensitive and complex topics (Payne et al, 1997, Hogwood, 1995). Governments have to contend with moral and complex issues and decisions made surrounding these issues require justification. It has been argued that "ministers may prefer not to have to justify particular decisions or recommendations" (Hogwood, 1995, 222) in order to avoid being the subject to criticism.

NICE is an excellent case for this point as a health rationing body. They base their technology appraisals of drugs on the Quality of Life measure (QALY). The QALY operates by measuring how much someone's life can be extended and improved and by taking into account costs of using the drugs to provide a year of the best quality of life available (NICE, 2013). For a lay citizen, this measurement of life may appear cynical and emotionless. This was the case in 2016 when NICE were called to re-evaluate the value of cancer drugs. This decision provoked widespread anger and discontent among pressure groups, patient groups, and the general public because this could mean that some potentially life-saving drugs would be phased out. The point is that it is NICE's role to respond to such criticisms and to publically defend their decisions rather than government. By using quangos, the government can steer negativity towards other organisations in a strategic attempt to manage political sensitivity and difficult economic decisions. Politicians do not have the in-depth medical knowledge and expertise required for making complex health-care decisions. Therefore, it is right, in some ways, that these complex decisions are made by participants in quangos and not by elected politicians who may actually lack the in-depth knowledge and expertise required to make informed decisions.

Governments use quangos to limit their responsibility because they can transfer some of their production rights (Theil, 2004). Thus, governments cannot be responsible for bad policy implementation. However, some quangos are aware of this transfer of responsibility. For example, NICE is not responsible for ensuring guidance and recommendations are

implemented. This is the responsibility of the particular healthcare provider and/or organisation. However, NICE have designed an implementation support package which includes support tools for implementation. This package is issued with each guidance document NICE publish to ensure widespread implementation of their guidance. As a consequence, it does become difficult for governments to "benefit from successful policy implementation, as it is no longer ascribed to them directly" (Thiel, 2004, 181). Involving stakeholders through quangos and guidance/policy development can be rather effective for implementation. This is because those stakeholders are likely to understand how and why the guidance was developed, help design more realistic policy that works on the ground and can feel empowered by being part of the process. This can result in good implementation. NICE, and quangos, therefore need to consult with stakeholders in order to have successful implementation.

To improve decision making and accountability, governments have sought to involve lay citizens. Through utilising quangos with a wider membership, it is argued that redistribution of power occurs (Quennell, 2001). This is because dominant stakeholders such as experts can be challenged by individuals who can contribute valid experiences or opinions towards decision making ensuring that policy making and service delivery is more efficient and scrutinised. However, it has been argued that experts can still dominate in these forums due to information asymmetries. Papadopoulos argues that "defining whose claims are legitimate or who can be considered as a credible stakeholder, and hence who should deserve recognition, is in reality often a matter of power struggle" (Papadopoulos, 2012, 133).

Given the increasing specialisation and fragmentation of society there is a need for quangos, however they do suffer from a number of democratic issues. In the next section quangos will be critiqued for their strengths and weaknesses.

## 3.4 Critique of Quangos

One problem with quangos is that they often do not last long (Grieve et al, 1999). This is because they are governmentally frequently created for a particular political agenda. Some may be created, abolished and then re-emerge with a different framework but with the original purpose and/or agenda. Thus, the varied nature makes it difficult to categorise, define and hold quangos accountable. This is problematic, making quangos unstable and is defined as "quango drift" (Thiel, 2004, 178). For example, a contract agency can become "a public body or a privatised organisation can be re-nationalised" (Thiel, 2004, 178).

Although separate, some quangos can be influenced by ministers through unofficial channels during informal meetings (Grieve et al, 1999). Grieve et al. remind us that the "public financing of quangos also gives politicians a strong instrument to influence quango activity" (Grieve et al, 1999, 140). Quangos can easily claim to be independent of autonomous organisations however bureaucratic constraints leave this autonomy challenging to achieve. For example, topics are referred to NICE by the DoH. This means that the U.K government essentially control NICE's agenda despite it being independent as they decide what topics NICE discuss. Given that the DoH controls which topic NICE discuss, there are questions around the extent to which deliberation in spaces created by the state support transformative discourses (Fischer, 2006). This level of steering and control may hinder transformative discourse to emerge. NICE however do have some element of control and autonomy as they select who participates in the development of guidance.

It has been argued that some quangos place power into the hands of "ministerial appointees who are not accountable for their actions" (Hunt, 1995, 204). This poses a problem for

accountability and widens the democratic deficit. Quangos make both "public policy and public expenditure difficult to direct and control from the centre" (Hirst, 1995, 341). This lack of central control is a further problem for accountability and legitimacy.

There is however an alternative perspective that argues that quangos can actually help to close the democratic deficit. The function of quangos, particularly in healthcare, is not "to remove management further from the people, but to be sure that decisions are taken much closer to the people" (Hunt, 1995, 205). Citizens are becoming increasingly involved in quangos. For example, parents and teachers are involved in decision making in education and tenants in housing associations. Thus, these individuals should be viewed as members of the communities they serve. Hunt (1995) argues that accountability does not come much more direct than that. The inclusion of citizens aims to close the democratic deficit between central government and society and quangos are required to have some mechanisms in place for citizen participation (Davies, 2007). NICE is an example of good practice where quangos engage a range of stakeholders in dialogue.

However, these citizens are often middle-class participants with time and resources available to them and are therefore not fully representative of all socio-economic backgrounds. Elstub (2007) further argues that as decisions become more complex, experts with in-depth knowledge are required and this makes it increasingly difficult to involve lay citizens because they lack the necessary level of expertise and understanding to equally and meaningfully participate. The involvement of citizens can be challenging to practically facilitate. Citizens may exacerbate conflict, particularly when it is political (McGarry and O'Leary, 2006) and therefore deliberation is left to elites who are more likely to display the 'spirit of accommodation' (Lijphart, 1975, cited by Caluwaerts and Deschouwer, 2013, 428).

It has been argued that appointments to some quangos have been made on the basis of political allegiances and donations and therefore appointments have received criticism (Elstub, 2008). Skelcher (1998) rightly notes however that the nature of political appointment may not be so problematic. This is because some quangos are still governmental bodies, therefore it seems a "perfectly sensible idea to appoint members who are willing to implement the policy of the government of the day" (Skelcher, 1998, 42). However, there are serious democratic failings with appointing on this basis. Public body appointments should be based on the appropriate person having the "necessary skills, experience and expertise" (Hunt, 1995, 197) to enable quangos to carry out its functions effectively and not based on political allegiance. It is argued that appointments are still "characterised by informality through third party recommendations and are structured around personal networks particularly within the NHS" (Skelcher, 1998, 41). This stands in the way of the diversity and plurality and it could be argued that the 'old boy network' mentality has not yet been swept away.

A crucial conclusion is offered by Hunt (1995). Quangos are a necessary evil in modern governance particularly with increased specialisation. Having said that, the major problem rests with how unelected actors can be held accountable for the important public decisions they make. What is important for existing quangos is that they are continually reassessed to ensure that their work still needs to be done and whether their current form represents the most effective and efficient way of getting it done (Hunt, 1995). This assessment can ensure that quangos are efficient and based on expertise.

NICE develops complex guidance which must take into account social and scientific judgments within tight financial constraints. This type of public activity requires some level of democratic functioning and their decision making processes should be democratically legitimate and accountable. As a quango, there processes should also be largely deliberative.

To empirically analyse quangos, NICE, has been selected as a case study. The second half of this chapter will discuss the rationale for carrying out case study research outlining its strengths and weaknesses and the chapter will conclude by discussing NICE.

## 3.5 Case Study Research

Case study research involves the close examination of specific cases such as people, topics, issues or programs. Researchers aim to examine each case expecting to uncover "new or unusual interactions, events, explanations, interpretations, and cause and effect connections" (Hays, 2004, 219). Case studies should be selected in the same way as the topic of an experiment is selected (Yin, 1994). For example, a preliminary theory is used as a template with which to compare the characteristics and empirical findings from the case(s). Case studies can include both qualitative and quantitative information.

Case studies have particular strengths. Firstly, they can be used to understand complex relationships due to their specific focus and this "facilitates the construction of detailed, in depth understanding of what is to be studied" (Hodkinson and Hodkinson, 2001, 3). A second strength to consider is that they are grounded in "lived reality" (Hodkinson et al, 2001, 3) and strongly relate "to the experiences of individuals, small groups, or organizations" (Hodkinson et al, 2001, 3). As a result of this, case studies retain "more of the 'noise' of real life than many other types of research" (Hodkinson et al, 2001, 3). Thirdly, case studies allow for the development of rich data which can support theoretical and conceptual development (Hodkinson et al, 2001, 7).

The main criticism associated with case study research is that one cannot generalise from a single case, therefore, the single-case study cannot contribute to scientific development

(Flyvberg, 2006, Hodkinson et al, 2001, Yin, 1981). Due to this, case studies are easily criticised, particularly by those who do not like the findings, using reasons such as "the sample was too small; it's not like that elsewhere; the researchers were biased" (Hodkinson et al, 2001, 10). A further criticism of case study research is offered by Yin (2012) who argues that there is also little methodological guidance. This however has started to develop given that case study research has become a popular method. It does have its own method and rationale (Yin, 2012).

In response to the main criticism outlined above, Flyvberg argues that while the case study involves the examination of a single example it can provide reliable information about the broader class (Flyvberg, 2006, 2). Drawing upon Karl Popper's 'all swans are white' example, he argues that just one observation of a single black swan would falsify the argument that all swans are white and in this way have "general significance, stimulate further investigations and theory building" (Flyvberg, 2006,11). As such, the case study is "well suited to identifying "black swans" because of its in-depth approach" (Flyvberg, 2006, 11).

Hodkinson et al (2001) respond to this by arguing that theory can be transferred beyond the original sites of study. For example, in this study NICE have been selected as the original site of study but other networks could be used to test the idea that networks may be viable institutions to combine micro and macro conceptions of deliberative democracy. This would simply add more empirical data in testing the theory.

Yin (1994) further argues that the level of generalization of the study results depends on an appropriately developed preliminary theory and study design. For this research, the case study approach has been selected as it is the most appropriate methodological approach. This is because it allows for an in-depth exploration of a case from which arguments / positions

can be falsified providing broader reliable information about a given process. The research position in this thesis is that as an example of a governance network, NICE may be an appropriate institution to combine micro and macro conceptions of deliberative democracy as they already employ deliberative democratic principles in their decision making processes (Daniels, 2008) and use deliberative methods to formulate guidance. The study has been designed to allow for broader evidence on the public health guidance development process to emerge as two PHAC processes have been explored rather than just one. The study also uses both qualitative and quantitative data to provide a richer data set. This rich data set provides in-depth insight into the PHAC process from a deliberative democratic perspective.

## 3.6 The National Institute of Health and Clinical Excellence as the Case Study

NICE is an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health (NICE, 2012). The government defines the Institute as a Non-Departmental Public Body (NDPB). More specifically however, it is an example of a contract agency quango (see section 3.2). NICE was established in 1999 by the Labour government to improve service efficiency and quality in the NHS. This was part of a strategy to set standards and monitor quality (Littlejohns, Knight, Littlejohns, Poole, Kieslich, 2016). Its purpose was to "bring an open and transparent approach to scarce resource allocation in an evidence based way" (Kelly, et al, 2010, 1057). This approach is interesting given that quangos are often criticised for not being particularly open or transparent. However, NICE developed within a policy context that emphasised the establishment of a new "statutory framework for patient and public involvement in healthcare" and patient centred services (Baggot, Allsop and Jones, 2005, 318). This development occurred because historically patients and service users in healthcare were characterised as "lacking the necessary resources, networks and contacts to engage with

government and to influence policy" (Baggot et al, 2005, 318). This is in line with Alfords Structural Model of Healthcare Politics (1975) which views healthcare policy making as being largely dominated by experts and professionals, despite the increased emphasis on quality of life issues from patient perspectives (Baggot et al, 2005, 329). Consequently, NICE aim to offer the NHS and wider health care partners "professional advice on how to provide their patients with the highest attainable standards of care and to reduce variation in the quality of care" (Littlejohns, 2009, 1).

## 3.6.1 Historical Development and Responsibilities

NICE is responsible for producing guidance which is largely structured around four areas.

These are technology appraisals, clinical guidelines, interventional procedures and public health guidance. This research is particularly interested in the development of public health guidance because public health cuts across many diverse populations and as a result decisions relating to public health should include those affected.

Over the last 10 years, NICE's role has changed significantly. In 2002, they established the country's first Citizens Council to advise its decision makers. The design and implementation of the group brought patients and public involvement into the health decision making context. This development aimed to move NICE away from expert based decision making.

In 2005, the "production of public health guidance on disease prevention and health promotion was added to the portfolio" (Kelly et al, 1057). NICE define public health broadly and includes a "range of activities from the most upstream assessment of national policy to the most downstream such as how a front-line doctor or nurse might give advice to an

individual on quitting smoking" (Kelly et al, 2010, 1057). As such, NICE public health guidance is concerned with disease prevention and health promotion.

NICE recognised that developing public health guidance would require different development methods than those used to develop other types of guidance such as in clinical guidance and technology appraisals. As such, the methods would have to evolve in order to deal with public health evidence (Kelly et al, 2010) including social evidence as well as medical / technical evidence. NICE realised that other forms of evidence, designs and methods would have be too scrutinised and included as part of the development process. This is an interesting development as one would expect to see new forms of evidence and methods being taken into account as part of the guidance development process.

In December 2014, The DoH started their triennial review on NICE. The focus being on whether NICE should continue in its current form, how NICE was performing and whether NICE is providing good feedback. A range of stakeholders were consulted in the review and the outcomes were largely positive. It was recommended that the functions of NICE continue and remain as a NDPB (Department of Health, 2015). NICE was viewed as a key high performing organisation that is trusted for its evidence based approach (Department of Health, 2015). Finally, the review recommended that "NICE's processes and methodologies would need to evolve in order to ensure it is fully aligned with the health and care system" (Department of Health, 2015). This research may then be of specific interest to NICE as it explores different ways in which it can improve the methods they use to develop public health guidance.

## 3.6.2 The Relationship with Deliberative Democracy

NICE has been studied before from a deliberative democratic perspective (Syrett, 2006, Davies, Wetherell and Barnett, 2006, Rawlins, 2005, Dryzek and List 2003, Gutmann and Thompson, 2002, Daniels, 2000) but research mainly focused on the NICE Citizen Council. Some have argued that NICE do not embody deliberative democratic principles, that they are simply a technocratic decision maker rather than a deliberative democratic decision maker (Syrett, 2006).

Others however have been more supportive of NICEs efforts at including lay citizens in the organisation and are tasked with deliberating moral and ethical issues (Davies et al, 2006, Rawlins, 2005). Atkins, Smith, Kelly and Michie highlight that organisations such as NICE "set up advisory groups that bring together stakeholders: those with the technical expertise to synthesize research evidence, those with clinical and public health expertise and those with relevant 'lay' or service user experience" (Atkins et al, 2013, 2). They state the model for decision making developed by NICE was explicitly based on deliberative democracy. Lastly, NICE has been labelled as a deliberative forum by theorists including Gutmann and Thompson (2002).

Theorists like Davies et al (2006) commend NICE for establishing a NICE Citizen Council. A commitment to deliberation underpins the design of the Citizen Council and after a number of design reviews, the Council has successfully become more aligned to a deliberative model (Davies et al, 2006). However, theorists like Syrett (2006) argue that those who label NICE as a 'deliberative body' are misleading and over-simplistic. Despite attempts to include the deliberation of patients, carers and wider health care communities he argues that decision making is still largely technocratic and expert led. Doubting that deliberative democracy can or should even be followed by NICE in relation to technology appraisals he argues that it seems "impossible to deliver both speedy and genuinely deliberative decision-making"

(Syrett, 2006, 892) especially where access to new treatments are concerned. This argument might apply to the development of public health guidance and is important to consider given the social, moral, ethical, technical and financial complexities needing to be addressed.

Rawlins (2005) argues that the procedural principles which underpin NICE decision making processes relate to the norms of deliberative democracy. These principles subscribed to by NICE will be described in more detail to shed light on how NICE embody deliberative democratic principles.

#### 3.6.3 Distributive and Procedural Justice

NICE subscribe to "widely accepted moral principles that underpin clinical and public health practice" and these include "respect for autonomy, non-maleficence, beneficence and distributive justice" (Littlejohns and Rawlins, 2009, 110). Distributive justice is concerned with allocating services in the fairest manner possible which clearly links with the deliberative democratic norm, equality. NICE recognise this as an important but complex responsibility and as a result have adopted two approaches "that can be taken to resolve such problems in publicly funded healthcare systems" (NICE, 2008). These include the utilitarian and egalitarian approach. The utilitarian approach to distributive healthcare expects "expenditure to be distributed in a manner that maximises the welfare of the whole population" (Rawlins, 2005, 471). The egalitarian approach however seeks for resources to be "distributed so that each can have a fair share of the opportunities available in a particular society" (Rawlins, 2005, 471). Both approaches are not fully subscribed to by NICE because both have For example, the utilitarian approach encourages already wide health weaknesses. inequalities which are apparent in society and the egalitarian approach has definition problems; the distinction between what is fair and unfair lacks clarity (Rawlins, 2005). NICE therefore seek to apply the principles of "procedural justice" (NICE, 2008) which has a focus on ensuring that the "processes by which healthcare decisions are reached are transparent, and that the reasons for the decisions are explicit" (NICE, 2008). This is where deliberative democratic principles are clearly evident in NICE. Reasoning and transparency are core norms of deliberative democracy.

Although NICE develop guidance through using different processes, all do follow the same procedural principles (Littlejohns et al, 2009). Procedural principles include scientific rigor, inclusiveness, transparency, independence, challenge, review, support for implementation and timeliness (NICE, 2008). NICE may be a suitable organisation to institutionalise deliberative democracy as there is already an established link between their procedural principles and deliberative democratic norms. However, this link could purely be an example of symbolic politics (Papadopoulos, 2012) where organisations claim to be following certain standards. This is why it is important to empirically explore NICE against the deliberative democratic standards.

## 3.6.4 Procedural Principles

Transparency directly links to the deliberative democratic norm of reason-giving and inclusiveness. Transparency is important in decision making, particularly when decisions affect wide client groups or specific target populations. It is vitally important that the process is open to all those affected by the decision. NICE aim to ensure transparency and inclusiveness by stating they allow a range of actors to participate and deliberate at different levels of public health guidance development. Transparency ensures that during deliberation, decisions made about limits on the allocation of resources, and the grounds for reaching them are made public. Reason giving produces better and fairer outcomes as it should include the

common good (see section 2.2.1). Through providing publically, well-reasoned decisions, NICE aim to ensure that the guidance they develop is legitimate by taking into account a range of discourses which include the best available scientific evidence along with ethical principles, preferences, aspirations and experiences. NICE aim to ensure that lay members involved in guidance development should be willing to reflect different experiences, rather than basing their views only on their own experience (NICE, 2008). Some training is provided for committee members including lay citizens but this is largely based on the process of guidance development and what would be expected of participants attending meetings. This encourages guidelines to be developed for the "greater good" rather than for selfish interest.

The process that NICE have adopted allows for the challenge and review of decisions which strengthens the opportunity for preference change. NICE have provided a forum which allows stakeholders, clinicians and experts to engage with everyday citizens. Each participant can take into account the opinions of different individuals which they might not normally have access to. For example, patients can offer their insight into "the practical and physical aspects of living with a particular medical condition" (Thomas, 2009, 21). In the NICE technology appraisal process, patients can submit a written patient statement which committee members consider (Staley and Doherty, 2016). This process may challenge stakeholders and experts to change their previously held preferences and to review their existing preferences and opinions. These statements can bring "meaning to data that does not reflect the realities of a patient's life (Staley et al, 2016). Similarly, experts may provide reasons for a decision that patients had never considered. Experts might draw upon clinical and economic data that helps patients understand why particular decisions might need to be made on these grounds. This transformation process is important for decision making because it ensures that decisions which are made are better informed as individuals review and challenge their existing pre-

conditioned opinions and arguments through being exposed to different information. This can also help participants develop rational and reasoned arguments for their preferences.

Health-care policies and issues are underpinned by complex scientific and social value judgments. Rawlins (2005) identifies that scientific value judgments are "concerned with interpreting the significance of available scientific and clinical data" (Rawlins, 2005, 472) however when dealing with such complex issues, scientific value judgments cannot be solely responsible for formulating decisions. This is because "expert scientists and clinicians have no special legitimacy to impose their own social values" upon decisions (Rawlins, 2005, 472). To ensure that the decision making process is inclusive of all voices and to move away from elitist decision making process, NICE have included lay citizens into the process. The public are a key stakeholder in all NHS decisions (Daniels, 2009,) and it is well documented throughout NICE literature that patient, carer and public involvement is a long-term strategy for the organisation. By involving such participants in the organisation, NICE aims to "produce guidance that addresses patient/carer and public issues, reflecting their views and opinions of experts.

NICE also use the QALY calculation as part of accepting and rejecting interventions. This concept may be viewed very different for a patient compared with an expert who may not be personally affected by the outcome of a decision. NICE state they also take into account social value judgements when developing guidance. Social value judgments relate to society and take into account the "ethical principles, preferences, culture and aspirations that underpin the nature and extent of the care provided by a health service" (Rawlins, 2005, 472). These values should ultimately "reflect those held by the people who are using, or who will use"

services (Rawlins, 2005, 472). It is therefore crucial that the views of the public and patients are incorporated and taken into account when forming healthcare decisions and guidance.

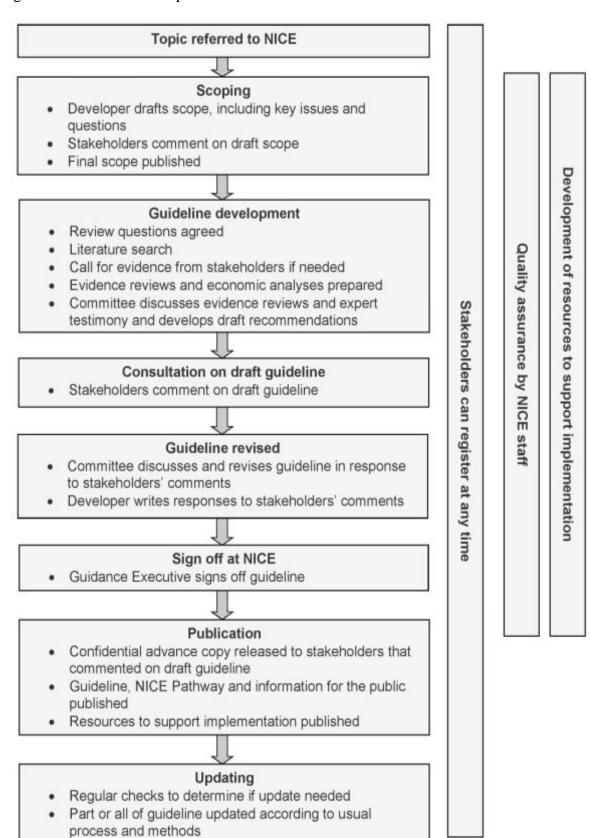
In theory, there already appears to be some evidence of the norms of deliberative democracy being institutionalised throughout NICE procedures. As a consequence, it may well be an appropriate institution able enough to combine micro and macro conceptions of the model. One particular area within NICE where this might be relevant and viable is in public health. This is because a range of evidence needs to be considered when developing this type of guidance (Kelly et al, 2010). Different discourses (type I and II) and types of evidence should be heard and considered by committee members. To achieve this, a combined approach to deliberative democracy would be an ideal model to institutionalise.

## 3.7 Development of Public Health Guidance

The development of public health guidance is of interest because it is concerned with preventing disease and health promotion. Topics are therefore varied and often concern the vast majority of the population. Topics might include smoking, alcohol or sexual health, weight management, pregnancy and mental health for example. The guidance developed should therefore be inclusive and representative to ensure democratic legitimacy.

Figure 3 produced by NICE (NICE, 2004) illustrates the public health guideline development process. A lengthy, complex procedure and depending on the topic, it normally takes between 12 and 27 months to develop guidance. The majority of the process involves deliberation at different stages including a range of participants.

Figure 3: Guideline Development Process



Source: NICE, 2004

PHACs are responsible for developing public health guidance and are tasked with complex decision making that could essentially impact on large amounts of individuals. They are a multi-disciplinary body which considers evidence and make recommendations for people working in the NHS, local government and in the wider public, private and voluntary sectors (NICE, 2012). They include a range of participants who are encouraged to deliberate and are an example of deliberative body in a quango that is part of a larger governance network.

Individuals selected to engage in a PHAC are defined as committee members. NICE state that members of PHACs are extremely varied however should include practitioners (both specialists in the topic and generalists), service or care providers or commissioners, and others working in the area covered by the guideline (NICE, 2012). In addition to this, PHACs should also include at least two service users, family members or carers OR members of the public/community or voluntary sector with relevant experience (NICE, 2012). These participants are known as lay members.

Organisations which have an interest in the guideline topic are also encouraged to register as stakeholders. This provides external organisations with an opportunity to influence the guidance. PHACs review comments submitted by stakeholders and are kept apprised of the guidance development.

PHACs are similar to micro conceptions of deliberative democracy. This is because PHACs are well-defined, contained structures which follow a formal process and are relatively small. PHACs are procedural, focused on formulating decisions and recommendations. They have elements similar to micro conceptions of deliberative democracy because topics are clearly set

in advance and participants are well-defined as we know who is participating in advance (Chappell, 2010). Due to these structural conditions, it is likely that type I deliberation is the most dominant type of deliberation used by committee members. To explore this argument further, the deliberative quality of PHAC meetings will be measured to gain a better understanding of the nature of deliberation taking place in these important micro structures and if this is linked to deliberation in the macro sphere.

#### 3.8 Conclusion

NICE is "leading the way in patient and public involvement" in healthcare and offers an exemplary service in how it engages with a range of actors (Littlejohns et al, 2009, 185). It has made attempts to incorporate citizens, researchers, experts, carers and healthcare professionals into their decision making processes which are largely deliberative (Davies et al, 2006). As an organisation, they attempt to be as transparent and open as possible in their processes explicitly stating that the model developed is based on the principles of deliberative democracy (Daniels, 2008). NICE however is an example of a quango located within a governance network who have both been criticised for being expert dominated, unrepresentative and inaccessible to the general public. Some of these issues have already been unearthed (Syrett, 2006). Due to these problems, networks and more specifically quangos like NICE, may benefit from combining micro and macro conceptions of deliberative democracy because it could potentially make them more inclusive, representative and therefore democratically legitimate. NICE could still develop evidence based guidance through consulting and making decisions with experts in the micro forums but ensure this is connected and representative of other discourses and arguments. They can do this by combining micro deliberation with the macro deliberation that takes place in wider

deliberative spaces. This may be a good model for NICE to consider in order to enhance legitimacy and accountability of the decisions and guidance they develop.

Much of the literature and research which is currently available on NICE has been written or commissioned by NICE and focuses on the NICE Citizen Council and the technology appraisal process. There is little research focusing on the quality of deliberation taking places in PHAC meetings and if this deliberation is connected at all to wider deliberation. Through case study research, this gap will be addressed. In doing so, the study aims to provide a deeper insight into the public health remit of NICE and this is required given the role they have in British healthcare.

# Chapter 4. Carrying out the Research and Exploring NICE

## 4.1 Introduction

The chapter will discuss the main data collecting and analysis methods which have been chosen to conduct this research and address the research aims. This chapter will firstly discuss the DQI as a tool for measuring the quality of deliberation in PHAC meetings, the strength and limitations of the coding framework and how the data was analysed using SPSS. The DQI is a framework which is used to test the quality of deliberation and was applied to samples from two PHACs developing vitamin D guidance and needle/syringe provision guidance. The DQI provides a measurement of deliberative quality however it has been criticised for not being inclusive of other important factors which might influence discourse such as tone and cues.

Secondly, the chapter will discuss semi-structured interviews and how they were used to gather data on the deliberation occurring outside the PHAC meetings. The strengths and limitations of this method will be discussed. The data was analysed using thematic analysis. Semi-structured interviews were used to gain in-depth qualitative accounts of committee members who were involved in the PHACs to describe the type of deliberation taking place outside the PHAC meeting. Semi-structured interviews are capable of providing rich quality data however due to the looser structure this can encourage interviewees to discuss non-related issues. The chapter will discuss how the data was analysed in more depth outlining how samples of deliberation were selected for DQI coding and how participants were selected to be interviewed as part of the research.

To conduct this research, ethical approval was granted by the University of the West of Scotland and met their ethical requirements. The project was also approved by the National Institute of Health and Clinical Excellence (NICE) and all formal documentation required to get access to NICE for research purposes is presented in appendix 1 and 2. All other supporting ethical documents are provided in appendix 3-7.

## **4.2 Deliberative Quality Index (DQI)**

The Deliberative Quality Index (DQI) is a quantitative methodological tool relevant for this research as it aims to produce measurements of deliberative quality assessed against deliberative democratic norms (see chapter 2, section 2.2 for detail). This framework was used to analyse samples of deliberation from the PHAC meetings to provide a measurement of deliberative quality.

The DQI is a theoretically grounded measurement instrument "that allows researchers to operationalize and quantify the quality of discourse" (Steenbergen, Bachtiger, Sporndli, Steiner, 2003, 22). There has been a movement towards deliberative politics and an understanding that political decision making should be more "talk-centric than vote centric" (Steenbergen et al, 2003, 21). The development of the DQI is an acknowledgement that this style of deliberative politics requires a formal framework in order to measure the quality of the deliberation that occurs during political decision making. A measuring framework is also important for other types of decision making, particularly when decisions affect a wide range of individuals, so a measurement of quality can be provided. The procedural principles outlined in chapter three and which are followed by NICE in decision making are in line with deliberative democratic norms (reason-giving, equality, transparency aimed at the transformation of preference). By using the DQI framework, this research can assess the

deliberative quality of the discourse in NICE PHAC meetings and measure whether it was deliberatively democratic.

The DQI is rooted in Habermasian Discourse Ethics and follows several rules as shown in figure 4. The six rules of discourse ethics (Steenbergen et al, 2003) highlight that rationality, similar to type I deliberation, is at the core of discourse ethics. Respect, open participation and justification for arguments are also core to the ethics of discourse. Each act of deliberation should aim to follow the rules of discourse ethics as closely as possible in order to produce "good" and meaningful deliberation.

Figure 4 Six rules of discourse ethics



The unit of measurement in the DQI is a speech. A speech can be described as "the public discourse by a particular individual delivered at a particular point in a debate" (Steenbergen et al, 2003, 27). The framework is only concerned with the relevant parts of speech. Relevant parts of speech are those which contain a demand, that is, "a proposal on what decision should or should not be made" (Steenbergen et al, 2003, 27).

The DQI has a coding framework which includes seven coding categories. The seven categories together "reflect how well a discourse corresponds to the principles outlined by Habermas" (Steenbergen, 2003, 27). The original DQI was developed to measure the quality of parliamentary discourse however the newest version of the DQI was used to code the samples of deliberation from the PHACs. The newest DQI was applied to PHAC meetings because it can be adapted to local contexts (Steiner, 2012) and is flexible enough to be more inclusive of type II deliberation. It has adapted to include story-telling which is an important characteristic to measure given that this is an element of type II deliberation and is of interest to this research. Story-telling is a personal source of evidence which patients / lay citizens often draw upon in deliberation. The newest version is therefore a useful framework to use since it has been adapted to include this type of deliberation. In one variable (level of justification) however, an older version of the DQI coding was applied to better interpret and describe the data.

The following DQI variables were used for this study; nature of speech act, participation, respect (listening, foul and respectful language), force of the better argument, level of justification and content of justification (common good and stories). The DQI does not specifically measure tone, body language and this is a limitation of the tool as these elements can change the meaning of discourse. For example, a respectful comment such as "that is a great idea" may be said in a sarcastic tone however the DQI does not take tone into consideration and therefore the true meaning of the speech act may not be captured. It measures the content of speech only.

A small number of variables were not included in the NICE coding. The meetings were recorded and transcribed externally. Meetings had approximately twenty-five participants and it was not always possible for the transcriber to identify who was speaking. Content of

justification (own group) was not coded because it was not possible to always identify who was speaking therefore trying to ascertain which group they were representing was not easily identified. A decision was then made to not include analysis of the content of justification (other groups). The rational for this was because if one could not establish which group the speaker belonged to, it was not realistic to truly distinguish if they were referring to their own group or another group. This had implications for measuring self-interest. Participation (length of time) was also not coded for. This was because timescales would not permit the actual timing of the length of each speech act which was coded.

# 4.2.1 DQI Samples

Recordings were taken from two vitamin D PHAC meetings and one NSP PHAC meeting.

Samples were taken from each of these full-day recordings. A total of 168 speech acts from the vitamin D PHAC meetings and 47 speech acts from the NSP PHAC meeting were coded.

This equates to a combined total of 215 speech acts.

Samples were taken from highly deliberative moments where exchanges of dialogue occurred rather than monologues. NICE set their PHAC meetings using an agenda which includes the presentation of evidence, question and answer sessions and discussions based on evidence, recommendations and stakeholder comments. No samples were taken from the presentation of evidence as this typically involved individuals presenting evidence to the committee and were monologues rather than an exchange of dialogue. Little deliberation occurred during these moments and was therefore classed as a low deliberative moment. High deliberative moments occurred when committee members were able to engage in dialogue with one and another, ask fellow members questions and exchange positions/preferences. Vitamin D samples were extracted from the review of evidence in the first meeting and from the expert

testimony discussion in the second meeting. NSP samples were extracted from the discussion of recommendations. This gave a good spread of the different parts of the guidance development process to assess the deliberative quality.

Frequencies were generated using SPSS and frequencies for each sample were analysed and are discussed in chapter five. The frequency data is compared with other studies which have used the DQI in a similar way in order to shed light on the data as there is no direct comparative data available. These studies will be introduced and described in chapter five.

# 4.2.2 Limitations of the DQI

The DQI is an appropriate tool to meet research aim 1 which is to measure the deliberative quality of micro conceptions of deliberative democracy such as NICE PHAC meetings. However, there are limitations to the DQI which should also be acknowledged. King (2010) suggests that the DQI does not capture the essence of participation with respect to Habermas's idea that all those affected by decisions should be ideally included in the process. The DQI does not provide a measure of the extent to which this is actually achieved (King, 2010). For example, the DQI was originally utilised in parliamentary commentary and the original debate focused on policies affecting UK society, particularly women. King (2010) argues that particular groups were not included in the deliberation and therefore not all views were represented in the discourse. The DQI measurement however concluded that normal participation took place. This finding is quite misleading.

Although the DQI is not concerned with the 'type' of person involved in deliberation, this is still an issue that need to be addressed. This research is concerned with healthcare issues that are focused on scientific and medical discourses. The type of individual more likely and

capable of using this style of discourse are often experts, doctors and clinicians who have developed the skills necessary to engage in expert deliberation. This type of participant occupies a "privileged place" (Moore, 2010, 720) within deliberative spheres because they are crucial to knowledge transfer and providing information. If there appears to be more or less of one particular type of participant involved in debates, the quality of the deliberation will be skewed towards who is actually participating. It could be argued then that the deliberative quality of PHAC meetings would naturally be of a higher quality because there are more experts participating who have developed those deliberative skills and knowledge required. The point is that the 'type' of person involved in the deliberation will ultimately influence the quality of the discourse and final measure. However, producing a high deliberative quality output is not simply enough in the eyes of deliberative democracy. A high deliberative quality measure does not necessarily mean the process is anywhere near democratic and the DQI fails to consider this point. Other methods are therefore required to address this such as interviews.

Having said that, the aim of the DQI is to measure the deliberative quality of discourse and assumes that deliberative democratic conditions such as participation and respect have already been met. The DQI is not necessarily concerned with the actual numbers or type of participants involved in discourse - it is a measurement of discursive quality. Issues concerned with democratic practice might be captured through other means.

Tone, body language and non-verbal cues are inherently important in studies with a direct focus on discourse. These qualities deliver, direct and inform messages that structure speech. The DQI does not include non-verbal communication. King (2010) emphasises that "a neutral statement may be delivered sarcastically, or accompanied by non-verbal communication suggesting disrespect or attempts to degrade the other participant. This may

be "obvious to the interlocutors but not identified by the DQI" (King, 2010, 5). The DQI therefore overlooks important cues that can change the explicit meaning of any discourse. However, being in a position to physically measure non-verbal cues such as body language and gestures may also have a negative effect on the quality of data being captured. Having a visible observer could influence participants to behave in a particular way meaning that a true representation of events is not captured. It was important to record the truest representation of the PHAC meetings as possible. For this reason, the researcher was not visible to the majority of committee members and did not engage in the process in any way. Access was granted by NICE to record meetings however it was also made explicitly clear that the researcher was an observer only and was not to engage in the process. This also placed limitation on being able to record non-verbal cues due the location of where the research was sat at the time of recordings.

Coder objectivity is another major criticism of the DQI. Since the coders observing the discourse are 'outsiders' they may not "have access to the inferences and subtleties such as judgements, and respect, which might exist between the participants of discourse" and misinterpret the true meaning of discourses (Steenbergen et al, 2003, 6). King therefore argues that "the DQI offers a hypothetical judgement about what is, for example, a good justification, without appealing to the participants it effects" (King, 2010, 6). However, the DQI relies on inter or intra coder reliability. Coders must agree "in their judgement that a particular indicator is applicable and if the indicator is deemed applicable, coders must agree on the code that a speech or other discursive text should receive" (Steenberger et al, 2003, 37). This ensures the validation of codes and that discourses are subjectively translated.

Coding was validated through intra-coding reliability. Just over 10% of the sample (23 speech acts) were selected from both the NSP and vitamin D samples and were re-coded four

years after the original coding. 11 speech acts were randomly selected from final NSP meeting where they discussed recommendations and 12 were selected from the first meeting in the vitamin D sample where the PHAC meeting reviewed evidence. The coding was then analysed for percentage agreements between the two same speech acts using an online tool called ReCal2. A percentage agreement is "the proportion of the number of units of analysis on which two coders' categorizations, scale values, or measurements match perfectly to the total number of units coded" (Krippendorff, 2011, 2).

Table 4 displays the percentage agreements between each speech act from the vitamin D sample. The table shows that the percentage agreement ranged 90-100%. This means that there was sufficient agreement between each set of coding and that the data is reliable.

Table 4 percentage agreement for vitamin D sample

Speech Act	Percent Agreement (%)
1	90
2	100
3	100
4	90
5	100
6	100
7	90
8	100
9	100
10	90
11	100
12	90

Table 4.1 displays the percentage agreement between each speech act from the NSP sample. The table shows that the percentage agreement ranged 80-90%. This means that there was sufficient agreement between each set of coding and that the data is reliable.

Table 4.1 percentage agreement for NSP sample

Speech Act	Percent Agreement (%)
1	80
2	80
3	100
4	90
5	90
6	100
7	80
8	100
9	100
10	90
11	90

The DQI is a method which gathers quantitative data as a measure of discourse however given that the DQI only provides a measure of deliberation, other methods were adopted to explore if macro deliberation was connected to the micro. This is a mixed method project and semi structured interviews were also used to gather qualitative data. The next section will discuss semi-structured interviews outlining their strengths and limitations. Section 4.3.1 will explain how the interview questions were developed using concepts from network analysis. Section 4.3.2 will discuss who was interviewed and how the data was analysed using thematic analysis.

## 4.3 Interviews

Qualitative data are mostly obtained through conducting interviews and are one of the most common data collection methods. They aim to go "below the surface of the topic being discussed, explore what people say in detail and uncover new areas or ideas that were not anticipated from the outset" (Britten, 1995, 311). Interviews vary in structure and style. There are three main types of interview identified by Britten (1995); structured using a structured questionnaire, semi-structured using open ended questions and in-depth where one

or two issues are covered in great detail with questions based on what the interviewee says. Semi-structured interviews were used in this research as there was a number of issues to explore therefore required some line of structure. This style of interview also allows the researcher to pursue ideas out of the responses provided and was the most appropriate style of inquiry.

Conducting interviews appropriately is important. To gain as accurate response as possible interviewers ought to be "interactive and sensitive to the language and concepts used by the interviewee" (Britten, 1995, 252). Good interviewers are responsive to participant cues and should be observant of gestures, facial expressions and tone of voice. The questions that are designed are extremely important as the response provided will be based on what questions are asked and how they are asked. Questions should be open ended, neutral, sensitive and clear to the interviewee (Britten, 1995). It is good practice to begin with questions that the interviewee can answer with ease as this can help establish rapport and trust between the unknown researcher and participant, making the interviewee feel relaxed. These standards were applied to the interviews for example, as an ice breaker the researcher briefly discussed the research aims, their overall interest in NICE and public health guidance due to their professional work in substance use. Interviewees were also reassured that they could be open and honest as no information would be passed onto NICE and they would not be directly named in the thesis to respect anonymity.

A number of issues should be considered when conducting semi-structured interviews. It is common for this style of interview to allow the interviewee to diverge into an area of non-interest to the research because of the looser structure. It is therefore important to maintain control of the interview. Three strategies for maintaining control include knowing the purpose of the interview, asking the right questions to get the information needed and giving

appropriate verbal and non-verbal feedback (Britten, 1995). Other problems with interviews include stage-fright, interruptions and presenting one's own perspective and potentially biasing the interview.

Interviews can be conducted and recorded in a variety of ways including note-taking during or after the interview, audio-taping, video-recording, telephoning and through social-networking sites. For this research, interviews were conducted through telephone and recorded and interviewees gave their consent to be recorded. The interviews were externally transcribed.

# 4.3.1 Development of Interview Questions

PHACs are an example of a micro conception of deliberative democracy because they are small, structured deliberative forums. Since PHACs are an example of a quango operating in a larger healthcare network, concepts from network analysis (Cinalli and O'Flynn, 2014) were used to help develop questions for the semi-structured interviews. These included density, centrality and betweeness. Density tells us about the overall shape of networks and if there is dialogue taking place outside the formal network. Centrality is concerned with the individuals involved in the deliberation and if there was any type of participant who would dominate deliberation. Betweeness assesses how deliberation filters to other deliberative spaces. This is important for assessing if micro and macro deliberation is integrated. Overall, the three concepts were used to design questions for committee members to discuss what happens in and outside a quango like NICE.

A higher density measure is better from a deliberative democratic perspective because the greater number of deliberative exchanges means the greater size of the argument pool. An example of an interview question to capture the density of the deliberation occurring outside

the PHAC meetings was "how many other groups do you contact during the guideline development process?" Further examples can be seen in the interview schedule (appendix 8). A high number of deliberative exchanges between members from PHAC meetings and those external from the process essentially means that some sort of discussion is taking place outside the formal process. It can also mean that there is cross-fertilisation occurring as individuals are being exposed to a number of different arguments and positions. This is positive as it could encourage individuals to develop refined arguments and positions, hear different information, ideas and opinions and potentially use this information in the development of the guidance they are involved in.

Given that the DQI does not take into account the type of participants engaging in deliberation, it is important to assess if there are key central players involved in the development of the guidance as they may be more influential than others. An example of an interview question aiming to capture centrality was "is one particular group/actor given more opportunities to speak during the process? If so, why do you think this is this the case?" This type of question aims to highlight if particular actors are more central to the process than others, for example experts or citizens. Once the most central actors have been highlighted in a network, acknowledging their roles is crucial. For example, are they topic experts, community members, how might their roles influence the style of deliberation they use and do they engage in deliberation outside the PHAC meetings?

Betweeness is another appropriate concept as it tells us the extent to which an actor facilitates ties between actors who are not directly linked to one and other. An example of an interview question focusing on betweeness used in the interviews was "do you speak to other organisations during the guidance development process?" This type of question helps establish if particular committee members engaged with others outside the PHAC meeting

and potentially acting as bridge builders. The concept of betweeness highlights those individuals who act as bridge-builders within micro networks. Bridge-builders are conduits of public discussion and debate. They engage in a range of deliberative forums and carrying the information between each forum. From a deliberative democratic perspective, these actors play an important role because they facilitate both the spread and content of arguments across the policy and public domain. These participants are considered important because they control the spread of information between actors and thus influence decision-making processes (Brandes, Kenis and Wagner, 2003, 243). If a micro network has a large number of bridge-builders then it could ensure that deliberative exchanges are possibly occurring external to the PHACs. Macro discourses can essentially be transmitted via bridge builders into PHACs making them more inclusive of wider discourses. From a deliberative democratic perspective, this is an important step in ensuring that deliberation is open and inclusive as possible.

Norms of deliberative democracy such as respect, changing preferences, inclusion, participation and influence were also used to help develop questions for the interviews. These are also important democratic characteristics which should be present when making decisions which affect others. The interview schedule can be viewed in appendix 8.

### 4.3.2 Interview Sample

Interviews took place after attending and recording the PHAC meetings to ensure committee members were aware of the research. Committee members were personally contacted after the PHAC meeting via email and invited to take part in a telephone interview. Telephone interviews were conducted as committee members lived across the U.K and face-to-face interviews were not feasible. Committee members were provided with an information sheet

and consent form to be completed prior to taking part in the interview. These can be viewed in appendix 6 and 7. A total of eleven interviews were conducted (table. 4.2). Two of those interviews were conducted with committee members who were members of both topic groups (NSP and vitamin D). Five interviews were conducted with members from the NSP PHAC meeting. This included one contractor / field-worker, 1 expert co-optee member, and three topic experts. Four interviews were conducted with members from the vitamin D PHAC meeting. This included two topic experts, one contractor / lead reviewer, and one contractor / health economist. Committee members were selected for interview because of their role within PHAC meetings. It was important to gain views and perspectives from different types of committee members as members do have different roles to play in meetings and therefore could have differing views and opinions. Table 4.2 illustrates that a total of three different contractors, five topic experts, one expert co-optee, one core member and one community member were interviewed. This is a good representation of all the different types of committee members present at PHAC meetings. Three committee members did not respond to initial and follow up contact and therefore were not interviewed.

Table 4.2 Interview sample from NSP and vitamin D PHAC meetings

	No of individuals contacted	No of individuals interviewed	Type of member
NSP	6	5	<ul> <li>Contractor / Field worker x 1</li> <li>Expert Co-optee x1</li> <li>Topic Expert x 3</li> </ul>
Vitamin D	6	4	<ul> <li>Topic Expert x 2</li> <li>Contactor /Lead Reviewer x 1</li> <li>Contractor / Health Economics x 1</li> </ul>
Both	2	2	<ul><li>Community Member x 1</li><li>Core member x 1</li></ul>
Total	14	11	<ul> <li>Core member x 1</li> <li>Community member x 1</li> <li>Expert Co-optee x 1</li> <li>Topic Expert x 5</li> <li>Contractors x 3</li> </ul>

In most cases the contact information of committee members was public through their professional work outside the committee. However, in cases where contact information was not public, NICE contacted the committee member asking if it would be appropriate to pass on their contact details to the interviewer.

# 4.3.3 Interviewing the Wider Network

During the interviews some committee members identified who they spoke to outside the PHAC meetings. These mostly included colleagues or organisations they were in regular contact with. A decision was made not to interview those other individuals and there were a number of reasons for this. Firstly, this research is not trying to capture the full extent of macro deliberation or trying to trace all instances of macro deliberation. It is interested in exploring the role of governance networks and if they can combine micro and macro

deliberation together in decision making. As a result, the core network was interviewed first and this included a small group. The second and most pressing reason was because of the way in which these interactions were discussed and viewed by the committee members. This was an area which required quite a lot of probing. Committee members did not view speaking to others as being of any real relevance or significance to the process and only a few committee members were able to provide actual names of organisations of whom they may have spoken with. It would have been difficult for the committee members to give specific names of the people they spoke to because what seemed to be occurring was very unstructured and unplanned discussions. For this reason, participants in the wider network were not interviewed. Having said that, it would have been beneficial to interview those involved in the wider macro discussion to explore if they had in turn discussed the issues with others to get a broader picture of the extent of the macro deliberation. This data might have provided a broader insight into the nature, style and type of the macro deliberation that was occurring out with the PHAC.

## 4.3.4 Analysis of Interviews

Analysis was performed on full transcripts using an a priori framework based on the research questions. The transcripts were read, re-read and annotated manually. Relevant quotes from each manuscript were selected and copied to an excel spreadsheet containing the framework headings/themes which acted as supporting evidence to the analysis and interpretation of the data. Names were omitted from the quotes however the committee they were a member of and their role within that committee were included. This is to highlight if there are any differences/similarities between the two committees and types of committee members. Professional roles were known to the researcher but were not included in the quotes to protect anonymity. The framework was adapted inductively as the analysis continued as broader

themes were identified. Individual responses which did not fit within the framework were noted in the spreadsheet to ensure that any important aspects were not missed, even if not arising as a common theme. Table 4.3 is the coding framework that was used to analyse the interviews.

Table 4.3 Coding Framework for Interviews

General / Deliberative	Centrality	Density and Betweeness	Other
Type of evidence presented by individual	Domination of type of evidence presented	Networking – Macro Deliberation	Involvement in original guidance (NSP only)
participate in the pro		Inclusiveness of process / representation	NICE selection (why)
Formality of process / Feelings of environment created		Benefits of inclusive deliberation	Skills of the Chair
Evidence of influencing the process		Challenges with a deliberative approach	
Challenges associated with including different types of evidence in the process		Transformation of preference	

# **4.4 Conclusion**

This chapter has discussed the main data collecting methods that was used to address the research aims set out in chapter one. Applying the DQI framework to samples from the selected PHAC meetings provides a deliberative quality measure allowing an insight into how respectful the process is in relation to listening and the type of language used by committee members. It also provides an opportunity to explore whether participants in the committees

provide well-reasoned and justifiable positions and arguments and if there is any change in relation to preference or positions occurred. The measurement tells us the overall quality of the deliberation within selected PHACs in NICE and to assess whether the deliberation is similar to type I or II deliberation.

It is however anticipated that due to the structural conditions and of the PHAC meetings and the type of participant involved in the meetings, that the discourse will be dominated by type I deliberation and as consequence be defined as an exclusive rather an inclusive process. It is therefore important to also explore if any deliberation outside this micro process occurs and if these discourses are connected. The interview data will provide this opportunity.

# **Chapter 5. The Quality of NICE Deliberation in PHAC Meetings**

## 5.1 Introduction

The first part of this research involves measuring the quality of deliberation occurring in NICE PHAC meetings. This chapter will present the DQI data from two NICE public health guidance development processes. The NICE data will provide insights into the type and quality of deliberation that emerges from this epistemic community. In the PHAC meetings, deliberation took place in a structured, formal and exclusive setting between participants that were mainly experts in the medical profession. This is very much in line with the characteristics of micro deliberation which is also structured and formal. It is therefore expected that the data will be similar to micro deliberation as defined by Hendriks (2006).

In this chapter interview data will be used to support the NICE DQI findings adding some interpretation to the data. Data from other studies will be used to shed some light on the quality of NICE deliberation in the PHAC meetings rather than being used as a direct comparator.

This chapter will discuss each DQI measure in turn. The measures which have been included in this analysis are; the *nature of a speech act* which explores the frequency of interruption, *respect* which is interested in the frequency of respectful listening, foul and respectful language used during deliberation. *Force of the better argument* measures the frequency of position change occurring in PHAC meetings and *level of justification* measures to what extent a speaker gives complete justifications for their positions / arguments. Lastly, the content of these justifications is measured including frequency of *reference to the common good and stories*.

Two NICE PHAC meetings held in London were observed and recorded (vitamin D and Needle Syringe Provision). Samples of the deliberation were coded using the DQI in order to measure the deliberative quality emerging from the PHAC meetings. This is an original study applying the DQI to PHAC meeting. There are no studies available which explore an epistemic community similar to NICE using the DQI. Due to this, a number of different studies have been selected to help make sense of the NICE data. The studies are used to get a clearer impression of the quality of deliberation in NICE and are not being used to make direct comparison. Direct comparison was not possible as the studies focused on different issues, participants of deliberation, political systems and time-scales. However they do help provide some meaning to the NICE data given the absence of direct comparative data. The studies which have been selected will be briefly discussed and the reasons for selection outlined.

Citizens (Belgium) – Caluwaerts and Deschouwer (2013) conducted nine deliberative experiments based on the topic of language and the division between Dutch and French speaking citizens in Belgium. This was an area of increasing deep societal cleavage. The study focuses on the involvement of citizens in deliberation and if they undermine deliberative quality. It also questions if strong decision making rules further impact on quality. A total of eighty-three participants were involved. The study has been included as a comparison because the participants were ordinary citizens. In the NICE PHAC meetings lay citizens could be present. Participants in the study were selected using a heterogeneity sampling method so there was variation in relation to gender, age and education. Deliberation was staged across three rounds lasting between a few minutes to one hour and thirty minutes with decision making occurring in the second and last round. No briefing material was handed out, moderators did not intervene and participants filled out questionnaires before and after

the study. Discussion topics were formulated in a broad way. This is quite different from the NICE set-up which was formalised, structured and heavily facilitated by a chair. The findings suggest that confrontation amongst citizens does not undermine deliberative quality. This study will be used to provide insights into the quality of citizen's deliberation. It will be used to assess if the deliberative quality is similar or different to committee members in an epistemic community.

Parliamentarians (U.K) – This study was conducted by Steiner, Bachtiger, Sporndli and Steenbergen (2004) and has been selected as an example of parliamentarian deliberation. The study applied the earliest version of the DQI to parliamentary debates (plenary and committee sessions) in Germany, Switzerland, UK and USA. UK data has been selected from this study. Participants involved in the UK study were Members of Parliament. This data provides opportunity to explore the deliberative quality of parliamentary discourse and bench mark this against the NICE deliberation highlighting any similarities / differences between NICE committee members and parliamentarians in relation to how they deliberate and the quality of deliberation. Parliamentarian deliberation is often described as being elite or expert deliberation. This study has been included as it provides examples of elite or expert deliberation which is an expected outcome of the NICE deliberation given the type of participants (expert) deliberating and the environment which they are deliberating in (formal / structured).

Parliamentarians (Switzerland) - The original parliamentary data discussed above was later reinvestigated for the use of stories in plenary and committee debates in Switzerland.

Bachtiger et al (2009a) focused on data from two debates on a language law in the constitution and on labor laws. Given that stories are a measure used in the new version of the DQI, it is important to include this case as a bench mark of assessing whether other forms

of communication such as storytelling is used more often by one particular type of deliberator and if it is dependent on the deliberative environment for example, micro or macro sphere.

Not all studies outlined above will be used to compare every DQI measure. This is because frequency data was not always available in each study for all the measures used in this study. The DQI is a flexible tool and depending on the area of interest, different variables can be explored and reported. Table 5 outlines which study is used to shed light on the NICE data.

Table 5: DQI variable and study applied

Variable	Study applied	
Nature of Speech	Citizen (Belgium)	
Force of the Better Argument	Citizens (Belgium)	
Respectful Listening	Citizens (Belgium)	
Respectful Language	Citizens (Belgium)	
Level of Justification	Citizens (Belgium)	
	Parliamentarians (U.K)	
Content of Justification: Common Good	Citizens (Belgium)	
	Parliamentarians (U.K)	
Content of Justification: Stories	Parliamentarian (Switzerland)	

The chapter will be structured in the following way. Firstly, the importance of each DQI variable will be discussed in relation to deliberative democracy outlining why the variables are an important standards to measure. For example, it is important to measure the frequency of respectful listening occurring in the PHAC meetings as this tells us if committee members are respectful to others and that committee members can engage in deliberation without being interrupted. Following this, data will be presented for the vitamin D and NSP samples alongside relevant data from the other studies. This is so the NICE data can be bench marked against other studies in relation to the deliberative quality and environment. Since no other study has applied the DQI to the public health guidance development process there is no baseline to compare the quality. However, given that NICE are responsible for making complex decisions that affect many individuals, the NICE data requires some level of

comparison in order to understand the quality of the deliberation that emerges from the PHAC meetings. The studies will be used for this purpose. Finally, reflections on the data will be discussed for each variable outlining the significance of the findings specific to NICE and also in relation to deliberative democracy and governance networks.

The data for each DQI measure will now be discussed beginning with the nature of the speech act which tells us about participation in the PHAC meetings.

# 5.2 DQI data - Nature of Speech

The nature of speech measures if participants were interrupted by others or if they were able to participate without interruption when speaking. This is an important measure to consider when exploring a deliberative environment as it tells us about the conduct of participants during NICE PHAC meetings. Participants of deliberation should be able to take part in free, unconstrained participation so they can engage equally in the deliberation. Participants should also demonstrate respect by listening to others and allowing each participant to speak as much as they want and complete a point they start without being interrupted. Low levels of interruption would signify a high deliberative quality because participants are able to deliberate and present their argument /position without being interrupted by other committee members. Given the formalised nature of the NICE PHAC meetings and due to the types of individuals deliberating, a low frequency of interruption would be expected.

Table 5.1 displays a) the frequency of speakers interrupting other speakers with a few utterances and b) the frequency of regular speech acts which includes all other speech acts in the vitamin D and NSP sample. The NICE data has been compared with the Belgium study to better understand it's quality in relation to the frequency of interruption and if committee

members in an epistemic community have a higher or lower frequency of interruption when compared with citizens.

Table 5.1: NICE and Citizen data – Interruptions (percentage and number)

	NICE (Vitamin D)	NICE (NSP)	Citizens (Belgium)
Interruption (a)	16.1% (27)	17.0% (8)	16.3%
Regular (b)	83.9% (141)	83.0% (39)	83.7%

The NICE data shows that there was a high frequency of regular speech (b). There were marginally few instances of interruption (a) in the vitamin D (16.1%) and NSP process (17.0%). The data shows that the process was relatively respectful. Committee members were able to speak freely without being interrupted and regular deliberation could take place.

The vitamin D and NSP data is very similar to the Belgium study which included citizens. The frequency of interruption was 16.1% in the vitamin D process, 17.0% in the NSP process and 16.3% in the Belgium study. The data in table 5.1 suggests that both committee members and citizens interrupt each other during deliberation at relatively the same frequency meaning there is very little difference in the deliberative quality between citizens and committee members with regards to interruptions occurring. Both citizens and committee members in an epistemic community engage in regular deliberation with few interruptions.

The NICE data indicates a good deliberative quality with regards to participation. This is because there was a relatively low frequency of interruption and deliberators could participate in a deliberative environment without being interrupted by others. These are characteristics of type I deliberation where equality is core to deliberation. Equality is measured in the DQI through interruptions (Bachtiger et al, 2009). Participants should have an equal voice where they can participate in an equal footing. Having a free and unconstrained deliberative environment is important as it encourages respect between participants.

The data in table 5.1 tells us that NICE committee members do not interrupt fellow members any more than other groups who deliberate such as citizens and that similar levels of interruption occur in different deliberative environments. It is interesting that the frequency of interruption is similar between citizens and committee members. The majority of committee members were experts from professional backgrounds and were likely to have experience of engaging in similar deliberative environments. They would ultimately know and understand the "rules of the game" (McLaverty, 2014, 41) of deliberative democracy. An even lower frequency of interruption might have been expected when compared with citizens who may not have the same level of skill or experience as experts.

Although the frequency of interruption was low, there were some instances of this occurring in the NICE samples and this could still indicate good deliberative quality. Interruptions can be viewed positively as vivid interactivity (Steiner, 2012). Examples of this were noted in committee meetings particularly when there was a contested area such as providing clean needles and syringes to under 16s. The act of interrupting might be due to a committee member being passionate or excited about a point being made and feeling the need to interject before the point has passed. Interruptions might also demonstrate that participants are actively listening to each other and to the points being made. In PHAC meetings where topics can be complex, it might often be the case that arguments pass relatively quickly due to the amount of evidence and information being presented in a tight timescale. The NICE data would suggest that given there are some instances of interruption there was elements of vivid interactivity with a relatively good level of respect between committee members. This would indicate good deliberative quality in terms of participation. The NICE data reflects the overall tone of the PHAC meetings that were observed during recordings. The meetings were very formal and structured with very few instances of interruption occurring. Most

participants were able to finish the point they had started and the chair played a role in facilitating this process. On occasion, there were some points of interruption. However, it was clear that committee members were expected to behave in a particular manner during meetings and this meant being respectful to others when they spoke.

## **5.3** Force of the Better Argument

The second measure to discuss is force of the better argument which is at the core of deliberative democracy because it is concerned with decision making being based on the better or rational argument. This does not mean that deliberation will always lead to consensus but rational arguments should enable participants to consider and perhaps accept the positions of others even if those arguments are not in line with their own. Dryzek (1990) argues that authority should not be based on anything other than good arguments so the force of the better argument also encourages equality in participation as it is the argument that is important; not who the participant is. This is particularly important in epistemic communities where experts are dominant and have a privileged place (Moore, 2010).

This measure can also tell us about preference change and when a better or rational argument has influenced committee members to change their preference i.e. the transformation of preference.

Coding was applied to speech acts when; a) there was a change in position and if reasons for this change were provided; b) when there was a change but no reference made to the arguments heard during deliberation; c) when there was no change in position but there was an acknowledgement that other positions have their value; and d) when there was no change in position and no acknowledgment of the value of other arguments heard.

Table 5.2 displays the frequency of position change in the vitamin D and NSP sample and this is presented with the citizen data in the Belgium study to shed light on how the NICE PHAC meetings compare with other deliberative environments in relation to preference change.

Table 5.2: NICE and Citizen data - Force of the better argument (percentage and number)

	NICE	NICE	Citizens
	(Vitamin D)	(NSP)	(Belgium)
(a) Changed position gives reason	6.0% (10)	0.0% (0)	0.7% (12)
(b) Changed position does not refer to	1.2% (2)	0.0% (0)	0.6% (10)
arguments heard			
(c) No change – acknowledges the value of	82.1% (138)	87.2% (41)	41.5% (691)
other positions heard			
(d) No change – no value acknowledged	4.8% (8)	0.0% (0)	57.2% (951)
(e) First time spoken	6.0% (10)	12.8% (6)	0.0% (0)

In table 5.2, the first two codes (a) and (b) refer to position change occurring. There was no position change in the NSP sample suggesting that committee members in this process were less likely to change their position when compared with the vitamin D process. This is because there was a slightly higher frequency of position change in the vitamin D sample.

Codes (c) and (d) in table 5.2 refer to no position change. In both processes, there was a high frequency of no position change but an acknowledgment of the value of other positions heard during PHAC meetings (c). There was a slightly higher frequency of this in the NSP sample (87.2%) when compared with the vitamin D sample (82.1%). Overall, this suggests that NICE committee members such as clinicians, doctors and professors are not likely to change their position but perhaps to remain respectful of and value the position of others.

When measured with the citizens in the Belgium study, the data in table 5.2 suggest that in different deliberative environments and with different groups of deliberators (citizens versus

committee members) position change rarely occurs as the frequency of no position change was higher than position change across all samples.

However, the data presented in table 5.2 shows that position change occurred more often in the NICE PHAC meetings when compared with the Belgium case. This is surprising as experts might be expected to have firmer views on issues than lay citizens as they possess higher levels of information, have probably given the issue more consideration and might be assumed to be less inclined to change position.

Overall, the data supports that there is very little position change occurring. The key difference is whether the value of other positions are acknowledged and this is higher amongst committee members (82.1% in vitamin D and 87.2% in NSP) when compared to other deliberators such as citizens in the Belgium study (41.5%).

Due to this, committee members may be described as being more respectful deliberators because they acknowledge the value of what others are saying and appreciate the value of their argument when compared with citizens. Citizens appear less likely to acknowledge the value of other positions heard. The frequency of no change and no value acknowledged in the Belgium study was 57.2% which was considerably higher when compared with the NICE data. There was no explanation for this provided by Caluwaerts et al (2013). However, this may have been the case because there was a deep societal divide and citizens did not appreciate the value the arguments of others.

The NICE data suggests that very few of the speech acts correspond to the habermasian ideal where a speaker acknowledges that the better argument changed his or her opinion. There was a very low frequency of this occurring in the NICE PHAC meetings. However, when

compared with other cases, NICE do have a higher frequency of this occurring across the two samples. There are very few empirical studies about the force of the better argument and it is difficult to establish whether positions are changed due to the better argument or for strategic reasons (Steiner, 2012) or even due to the topic under deliberation. Together the cases show that at both expert and citizen level it rarely happens that deliberators "explicitly acknowledge that they have learned from each other and correspondingly change their position" (Steiner, 2012, 150).

The data corresponds well to what committee members discussed during the interviews.

Members stated that they had learned from others and were exposed to other perspectives but that this did not necessarily influence them to change their own preference or position. Only a few stated that this had actually occurred.

Despite the low frequency of position change, committee members in the interviews spoke about the importance of deliberation allowing them to hear different position, information and evidence. Even if position change does not occur there is still value in deliberating and encouraging this between different individuals even if only between different committee members.

"...the actual process of being involved was learning itself, you know, not just about the process but about the research you heard etc and the different perspectives. So it did allow for that opportunity" (Topic Expert, NSP)

"There' so much more about NICE that I never really understood until I worked with them and my position on NICE has changed...I tend to form my own very strong views and will listen to both sides and then from that form my own view. So I wouldn't say I've particularly swayed but I think from the whole point of NICE, my whole way of looking at things has been very different" (Community member, NSP and VD)

It is also clear that different people play a role in influencing position change. The comments below from interviews highlight that certain members can provide information or knowledge that challenges original positions encouraging individuals to reconsider. Topic experts were named as being particularly influential in the deliberative process. This may be because they have specialist knowledge in the area.

Interestingly, one topic expert in the NSP process said that a community member who was a service user representative provided a very different insight to what other members provided and because of this were highly influential.

"I'm thinking of a user representative (community member)...she sort of made me see things, she was probably the most influential person in that respect, that she gave a very different insight" (Topic Expert, NSP)

This particular type of committee member brought a service user perspective to the deliberation and given the notable gap in representation from those who access services, this was an important role to highlight as they may have presented a very different type of evidence / experience. There is a need to include service users in deliberation as they can provide a very different account from other members such as topic experts and can enrich the deliberation by bringing their experience and knowledge to the table. Service users may also play an important role in changing the positions of those committee members who are removed from the reality of living with certain conditions and the real impact decisions have on their day to day lives. This notable gap of service user involvement needs to be brought to the attention of NICE.

The NICE data has highlighted that some participants may never agree with the other, but may recognise that the other side also has a valid point (Steiner, 2012, 151). This recognition might simply be enough where the topic under deliberation is highly complex involving an epistemic community. This is because the process of deliberative transformation takes times (Curato et al, 2017). When a variety of individuals are involved in deliberation, the argument

pool may be larger and individuals require time to be able to consider and change their preferences. The NICE data suggests that while committee members are not particularly influenced by others to change their position, they do respect and value the position of others and that some types of individuals may influence position change more than others.

# **5.4 Respect**

The third measure to consider is respect. Respectful listening, foul and respectful language has been grouped under the theme of respect to provide an overview of this measure in the PHAC meetings. Concepts such as the force of the better argument and level of interruption are important measures in relation to deliberative quality however they are underpinned by respect, and respect has an impact on other standards. Respect ensures that participants can openly present their positions and arguments without fear of being attacked, feeling unequal and be sure that others are listening to what they have to say. The data in table 5.1 and 5.2 suggests that NICE committee members do listen to what others have to say as there is a high frequency of acknowledging the value of other positions heard and there are low levels of interruption. This cannot be done without respectful listening. A high frequency of respect in terms of listening and respectful language in NICE PHAC meetings would signify high deliberative quality and is expected from this epistemic community.

#### 5.4.1 Respectful Listening

Table 5.3 displays the frequency of respectful listening occurring in the NICE PHAC vitamin D, NSP sample and the citizen data. The NICE data for both processes has been presented with the Belgium frequency data to shed light on how the NICE PHAC meetings compare

with other deliberative environments in relation to the frequency of respectful listening occurring amongst committee members and citizens.

Coding was applied to speech acts when; a) the speaker ignored arguments/questions addressed to him/her by other participants; b) when the speaker did not ignore arguments/questions addressed to him/her but distorted these; c) when the speaker did not ignore arguments/questions addressed to him/her by others and engaged with the arguments/questions in a correct and undistorted way; and d) when no argument/question was addressed to the speaker.

Table 5.3 NICE data - Respectful listening (percentage and number)

	NICE (Vitamin D)	NICE (NSP)	Citizens
			(Belgium)
Ignores (a)	0.6% (1)	0.0% (0)	12.0% (200)
Distorts (b)	5.4% (9)	0.0% (0)	13.1% (218)
Engages (c)	88.1% (48)	91.5% (43)	63.5% (1056)
None (d)	6.0% (10)	8.5% (4)	11.4% (190)

Table 5.3 shows there was a little or no frequency of speakers ignoring arguments/ questions in the vitamin D (0.6%) and NSP (0.0%) meetings suggesting that committee members in both processes were engaged and listened to by their fellow committee member because they did not ignore them. This is a characteristic of type I / micro deliberation where participants are "willing to listen to each other" (Hendriks, 2006, 492).

The data in table 5.3 supports that there was a high frequency of speakers engaging correctly and in an undistorted manner with arguments/questions presented to him or her in the vitamin D sample (88.1%) and NSP sample (91.5%). There was a slightly higher frequency of this in the NSP process suggesting that NSP committee members were more engaged with regards to listening and being more respectful.

The interview data is useful to draw upon here in light of the DQI data. Committee members did express that they were listened to and felt respected due to others actively listening to them and engaging with their arguments. It is also interesting that there is a range of different types of committee members (community member, topic expert and core member) expressing that they felt respected. The comments below reflect the data in table 5.3.

"I do feel very included and very listened to, particularly by the chair" (Core Member, NSP and VD)

"I do feel that the groups that I've been involved in are happy to listen to what you've got to say and will kind of think about it. Occasionally they've come to me in the breaks and say oh that was really interesting your comment" (Community Member NSP and VD)

"By the afternoon I'd felt from that first day particularly that there was team work going on, I felt valued, the chair made me feel valued and listened to and I think that worked well" (Topic Expert, VD)

Overall, table 5.3 shows that in the NSP and vitamin D samples, there was a higher frequency of respectful listening occurring when compared to the Belgium case. This is because a higher frequency of committee members engaged correctly with arguments in a correct and undistorted way; 88.1% in the vitamin D process, 91.5% in the NSP process and 63.5% in the Belgium study. This suggests that committee members are more respectful in relation to listening when compared with citizens because there was a much higher frequency of this occurring in the NICE PHAC meetings. The fact that the topic under deliberation was highly contested amongst citizens in the Belgium case, might explain why there was a higher frequency of ignoring and distorting the arguments of others. The deliberative environment was much more fractious and divided when compared to the NICE deliberative environment which was calm, formal and professional.

5.4.2 Language; Respectful and Foul

Table 5.4 displays the frequency of respectful and foul language being used by speakers towards another participant. Coding was applied when; a) the speaker used respectful language towards another participant; and b) when foul language was used. The DQI instructs that respectful language should be considered on a spectrum and include statements such as "your argument is truly brilliant to your arguments are not bad" (Steiner, 2012, 269).

In terms of foul language, coding was applied to when speakers used foul language to attack other participants on a personal level which included mild foul language such as "you are a liar" but also statements such as "you seem confused" (Steiner, 2012, 269).

Table 5.4: NICE data and Citizen data - Respectful Language (percentage and number)

	NICE (Vitamin	NICE (NSP)	Citizens
	<b>D</b> )		(Belgium)
Respectful language used (a)	17.9% (30)	10.6% (5)	10.2% (169)
Foul language used (b)	4.8% (8)	2.1% (1)	4.1% (68)

In terms of respectful language (a) there was a slightly higher frequency of this occurring in the vitamin D sample (17.9%) when compared to the NSP sample (10.6%). Comments such as "that's a really important point" and "fair point" were coded as being examples of respectful language being used by committee members. The data suggests that vitamin D committee members were perhaps slightly more respectful as they used more respectful language. Overall however there were few instances of respectful language being used.

A slightly higher frequency of committee members used foul language (b) to attack other members in the vitamin D sample compared with the NSP sample; 4.8% compared to 2.1%. These were defined as un-personal attacks. Examples of foul language being used by committee members in an un-personal way included "I think we will park it there", "that's a slightly complicated answer" and "it's blindingly obvious". These statements however were rarely used.

The data in table 5.4 suggests that committee members in the vitamin D process were more disrespectful in relation to the language being used towards their fellow committee members when compared to the NSP members. The key point here however is that there was very few instances overall of foul language being used by committee members.

Table 5.4 shows that the data for the NSP sample is very similar to the Belgium research in relation to respectful language used. Across all samples foul language was rarely used during deliberation between committee members and citizens as the frequency of this occurring was generally low. This is interesting given the fractious environment that citizens were deliberating in.

The figures for both respectful language and foul language are low suggesting that the language used across all samples is neither respectful nor disrespectful. This is the case for both citizens and committee members.

Respect is quite difficult to empirically measure as "respect may be used strategically to further one's interests" (Steiner, 2012, 109). For example, participants may agree with the position of another participant and make respectful comments but in reality they don't agree with the position. This might happen to win participants over and to get them on their side if the topic under deliberation is quite contested. This could explain why a higher percentage of committee members engaged appropriately with arguments / positions presented to them i.e. for strategic reasons. The epistemic community might be quite competitive. Committee members may have behaved in this manner so NICE would view them as a respectful committee member rather than someone who was difficult or who challenged the framework which seemed already pre-set by NICE.

Standards of deliberation depend on context and this may explain why neither high levels of foul or respectful language were used. If context is applied to the NICE data, the findings in relation to language are not surprising. Committee members were brought together under a context to provide their expertise, knowledge and to deliberate with each other on the best available evidence in order to develop public health guidance. It is also in line with type I / micro deliberation where a small group of like-minded individuals are brought together to deliberate on a topic (Hendriks, 2006) and engage in respectful deliberation. The NICE data is beginning to resemble expert deliberation where being selected for expertise and competence is a feature common to expert deliberation (Moore, 2016, 196).

Foul language and personal attacks would not be typical in this context. One would expect there to be no previous conflict between participants therefore few personal attacks would be made. Committee members included Professors, Medical Directors, Consultants and Analysts. It would therefore be surprising if such professionals would use foul language, make personal attacks and ignore or distort arguments presented to them due to their understanding and professional conduct during meetings. Individuals such as experts would also have previous experience of engaging appropriately in deliberative forums and have a level of education and training. They essentially know the deliberative democracy "rules of the game" (McLaverty, 2014, 41).

Steiner explains that limits should be set on language. He argues that there is no place in deliberation for disrespectful arguments supporting that for a "good deliberative culture it is important that proper language is used" (Steiner, 201, 122). This appears to be the situation in the NICE PHAC meeting. Arguments can still be advanced in forceful and tough ways but without offensive language being used. What is important is that participants of deliberation

refrain from making personal attacks. It is also vital for participants to engage with questions/arguments presented to them in a correct and undistorted way in order for participants of deliberation to feel respected as a member of the deliberative forum. Good deliberation should be "respectful but at the same time lively and spirited" (Steiner, 2012, 123).

Since there are some instances of disrespectful language in the PHAC meetings, the interview data can be used to explore this further as some committee members spoke about times when they did not feel particularly respected. One committee member who was involved in both the NSP and vitamin D process felt she was respected but sometimes felt 'over-looked' and was viewed by other committee members as being there to simply 'tick a box'. The member felt that this was the case for community members in general and was not just specific to one particular topic group.

"I do feel respected I just think sometimes we're a little bit overlooked because sometimes I wonder whether other members on the committee think oh we're just there to tick a box maybe...that's how I felt across the board really" (Community Member, NSP and VD)

A different committee member who was a topic expert expressed that they would have felt more respected as a participant if they have been given feedback from NICE as to why they did not take on board the comments they had made regarding the topic issue.

"I think I'd feel more respected if I did have some feedback on why they were not taking on my comments" (Topic Expert, VD)

Topic experts were named by two committee members as not being particularly respectful of others members. It was perceived that topic experts viewed other members as 'non-expert'

or 'tokenistic' members of the group and found them to be disrespectful of their views and opinions.

"At first I didn't feel very respected, I kept getting told I was wrong...I thought oh no, I've just volunteered to be the nasty cop on all of these committees. Because I felt some resentment sometimes from the topic specific advocates. I'm an academic; they don't always respect the academic processes in terms of the evidence. So I didn't feel completely respected" (Core Member, NSP and VD)

"Yes and no...I'm a health economics expert but not on that particular topic and I kind of sense their (topic experts) unease when this happens and somebody like me stands up and starts to present a model...I think different experts take it in different ways" (Review Team, VD)

"Other times they (topic experts) just get very frustrated at certain thing, this is stupid, you've got a non-expert coming in and making these big decisions...and you can tell they're frustrated at the system and in that sense I'd say we probably don't feel respected, we very much feel like the bad guys coming in and being the cold hearted economists" (Review Team, VD)

Members should feel respected within any forum in which they are engaging in so they can communicate openly and with confidence. In the NICE deliberative environment, respect seems related to the fact that each member is assigned a role/title. For example, members can either be defined as a community member or topic expert. Some may assign a hierarchy to these titles/roles. When an individual is assigned the role as 'expert' one assumes they have heightened knowledge and information and therefore are more respected because of this title. As Moore (2010) suggests, they are given a privileged place. This can be problematic in relation to equality because not everyone is participating equally. More weight may be given to the evidence presented by experts when compared to other types of committee members because it is assumed they have better or more knowledge in the area. Experts are however not always right and the role of experts in deliberation is contested. Gutmann and Thompson (1996) claim expertise can never answer moral and political questions however experts are necessary due to complexities and knowledge they bring to a process (Brown, 2014). This is particularly true in healthcare where topics under deliberation can be highly complex and dominated by medical jargon. NICE may want to address this issue by looking at the

language they use to identify and assign roles to committee members. Do people require a title or role to engage in deliberation? NICE could consider not assigning roles/titles to members so there is less perceived hierarchy and this may help members feel more respected as an equal participant in the process rather than being viewed as 'tokenistic'.

The DQI and interview data support that in general there was a relatively high level of respect in terms of listening. There were a few instances where committee members felt disrespected throughout the process and these were highlighted through quotes from committee members. When context is applied and looking at the types of participants involved in the deliberation, the findings are not surprising. One would not expect professionals and experts to be terribly disrespectful. The deliberative environment in relation to respect appears relatively neutral.

#### **5.5** Level of Justification

The next DQI measure to discuss is level of justification. This measure provides insight into the level of justification participants apply to their arguments. King argues that "justification emphasizes the requirement for reason to involve clear links between premise and conclusion" (King, 2010, 3). Justifications can be sophisticated or average. It can be defined as sophisticated if it is linked to the topic a number of times and rational reasons provided. Justifications help participants of deliberation engage rationally in discourse and also has a role to play in the transformation of preference as good justifications could potentially persuade a participant to change their preference. Non-rational justifications might encourage participants to solidify their initial preferences.

In table 5.5, frequency data is displayed for the NICE vitamin D and NSP data for the level of justification provided. There are six levels of justifications. Coding was applied to speech

acts when; a) the speaker did not present any arguments, for example asks for additional information; b) when the speaker only says that X should or should not be done but no reason is given for why X should / should not be done; c) when the speaker justifies only with an illustration why X should / should not be done; and d) when the speaker gives a reason Y why X should / should not be done but no linkage is made why Y will contribute to X. Coding was applied to speech acts when; e) the speaker gives a reason Y why X should / should not be done, and a linkage is made why Y will contribute to X and, coding was applied when; f) the speaker gives at least two reasons why X should be done and for at least two reasons a linkage is made with X.

Table 5.5: NICE data - Level of justification (percentage and number)

	NICE (Vitamin D)	NICE (NSP)
No argument presented (a)	13.7% (23)	6.4% (3)
No reason given (b)	20.8% (35)	27.7% (13)
Justified with an illustration (c)	4.8% (8)	12.8% (6)
Reason given but no link made (d)	13.1% (22)	6.4% (3)
Reason given and 1 link made (e)	39.3% (66)	44.7% (21)
Reason given and at least 2 links made (f)	8.3% (14)	2.1% (1)

In table 5.5, the data shows that there was a high frequency of reasons being provided and a link being made to the topic in both samples (39.3% in Vitamin D and 44.7% in NSP). This means that committee members provided reasons for their positions and arguments and were able to link this to the topic under discussion so a rational link was applied. This could be described as a reasonable sophisticated level of justification.

In the comparison cases, an older version of the DQI was applied and therefore the codes are labelled differently. Given that the newest version of the DQI was used to code NICE deliberation (see chapter four, section 4.2 for detail), the NICE data has been re-defined so the data could be properly compared using the older DQI coding. Codes (e) and (f) in table 5.5 have been added together in table 5.6 to define a sophisticated justification.

Table 5.6 displays the NICE data compared with the citizens in the Belgium and UK parliament data to explore at what level do different groups justify their positions and if there are any similarities / differences between groups.

Table 5.6: NICE, citizens and UK parliamentarian data - Level of justification data (percentage)

	NICE	NICE	Citizens	Parliamentarians
	(Vitamin D)	(NSP)	(Belgium)	(UK)
No argument presented (a)	13.7%	6.4%	n/a	n/a
No reason given (b)	20.8%	27.7%	18.0%	12.9%
Inferior justification (c)	4.8%	12.8%	27.0%	29.0%
Qualified justification (d)	13.1%	6.4%	12.0%	12.9%
Sophisticated justification (e)	47.6%	46.8%	38.5%	45.2%
Total	100.0%	100.0%	100.0%	100.0%

In all cases, there was a higher frequency of sophisticated justification (e) being provided compared with any other level of justification. Committee members (47.6% in Vitamin D and 46.8% in NSP) and parliamentarians (45.2%) appear to apply sophisticated levels of justifications for their arguments at similar frequencies. Citizens in the Belgium study provided slightly less sophisticated justifications (38.5%) compared with committee members and parliamentarians.

The data suggests that experts, citizens and parliamentarians can all provide sophisticated justifications for their positions when deliberating together. In all the studies, the participants of deliberation were made up of the same type i.e. experts, citizens and parliamentarians and when deliberating together participants can provide sophisticated justifications. It is not clear what might happen if bringing all these participants together would change the frequency of sophisticated justifications being provided. It is interesting for NICE to note however that citizens can also provide sophisticated justifications for their arguments. It is not only experts who can provide well-reasoned and rational arguments. By involving more citizens, this could make the NICE process more inclusive.

Given that there is a high frequency of sophisticated justification in the NICE PHAC meetings, this suggests that high quality reasons and justifications are being provided by committee members and this is a characteristic of expert deliberation. This is because arguments must be of a high quality, justified and reasoned. Having said that, while it is ideal that NICE committee members apply sophisticated levels of justification to their arguments, this might not actually mean that the deliberative environment is democratic. The process could still be quite exclusive in terms of other democratic standards such as participation and equality. When exploring the type of participant engaged in the NICE PHAC meetings, participation was mainly made up of experts and there was little input from other types of participants such as service users, carers or lay citizens. This makes the process quite exclusive despite a high deliberative quality.

### 5.6 Content of Justification - Common Good

The fifth measure to consider is common good. While it is important to measure the level of justification participants provide for their arguments in relation to deliberative quality, it is also interesting to know the content of those justifications. For example what subjects / reasons are participants using to justify their argument? For this study, common good and stories have been included in the analysis as examples of content used to justify positions.

In early versions of deliberative democracy, common good was essential to the process because it ensured that self-interest was excluded and that decision making was based on the common good or public interest. Common good encourages participants of deliberation to take a more broad view of important decisions. In healthcare and for NICE perhaps, this is exceptionally important because public health essentially spans across many different

populations. Given that NICE are interested in social value judgements as well as scientific assessments, there might be a high frequency of reference to the common good as this is underpinned by social value judgements. Common good is also a core characteristic of type I / micro deliberation. This is because in micro conceptions of deliberative democracy participants should be "committed to reaching a mutual understanding in view of the collective good" (Hendriks, 2006, 492).

Table 5.7 displays frequency data for the NICE vitamin D and NSP samples. This has also been compared with citizens in the Belgium sample and parliamentary data in a public setting. The parliamentary data has been used to explore if setting influences the content of justification i.e. does deliberating in public encourage a higher frequency of reference to the common good. NICE do allow the public to attend PHAC meetings however there were very few observers at the meetings observed in this research. The citizen data has been used to explore if committee members refer more to the common good when compared with citizens.

Coding was applied to speech acts where; a) the speaker referred to benefits and costs for all groups represented in the deliberation; and when b) the speaker did not refer to benefits and costs for all groups represented. Examples of the common good in the NICE samples included reference to whole population approaches, free, universal, low costs supplements for all groups, and universal policies.

Table 5.7: NICE, citizens, parliamentarian public data - Common good data (percentage and number)

	NICE (Vitamin D)	NICE (NSP)	Citizens (Belgium)	Parliamentarians (UK, Public)
Refers to all	13.7%	19.1%	7.0%	30.5%
groups				

In table 5.7, there was a higher frequency of speech acts referring to the common good in the NSP sample (19.1%) when compared with the vitamin D sample (13.7%). This difference perhaps may be due to the topic under deliberation. Committee members in the NSP sample felt that it was more relevant to justify their position by referring to the common good in this topic.

The highest frequency of reference to the common good was by parliamentarians in public settings (30.5%). In the NICE PHAC meetings, there was slightly more observers in attendance at the NSP PHAC meetings when compared with the vitamin D meetings and the more public nature could explain why there was a higher frequency of referring to the common good when compared to the vitamin D sample.

The data shows that when compared with the other cases, citizens rarely refer to the common good when providing justifications for their arguments. This may be because the topic under deliberation was contested and therefore participants were voicing their own concerns rather than the common-good. They may have been more self-interested.

When compared with citizens, NICE committee members appear more likely to justify their arguments using the common good. Again, this may well be dependent on the context and the topic of deliberation. Public health guidance makes recommendations for populations and individuals on activities, policies and strategies that can help prevent disease and improve health. Given that public health focuses on large populations and on prevention and improvement of populations, it is maybe not surprising that committee members involved in developing public health guidance make more reference to the common good than other types of deliberators i.e. citizens.

In the interviews, some committee members discussed the type of expertise and information they brought to meetings. Two committee members interviewed were members of both the vitamin D and NSP PHAC meetings. One was a community member and the other was a core member. Both said that their role was to provide a generalist, humanistic perspective evidencing that some members do think about the wider impact that the guidance will have i.e. the common good.

"I bring this humanity, you know, to the guidance in a way where some of the professionals can get wrapped up in all the compounds and chemicals" (Community Member NSP, VD)

"The expertise that I said that I would bring to it was expertise in health related behaviour change...Quite a lot of expertise in taking the patient perspective and communication with patients and the general public" (Core Member NSP and VD)

The DQI and interview data support that on occasion committee members were able to move beyond self-interest while developing public health guidance when compared with other deliberators such as citizens. This has been supported in other NICE research where members were described as being able to provide a "generalist perspective" and "ability to relate things to the real world" (Ursu et al, 2010, 21).

Overall however, there was a higher frequency of no reference being made to the common good in the NICE samples which is surprising given that NICE are concerned with social value judgements. The frequency of reference to the common good was expected to be higher given this emphasis. The deliberation appears very much in line with expert deliberation which "typically does not address moral norms or the common good in any direct way" (Moore, 2016, 196). This is further echoed by committee members who expressed that NICE based their decisions on technical judgements such as facts and statistics rather than on moral norms. The comments below are provided by committee members involved in the NSP

process who clearly felt that the process of developing guidance was primarily led by evidence.

"...I think the fact that they make decisions based on evidence is absolutely excellent and that's what they're looking for. So whether it's external people they bring in or whether it's the committee themselves, it always comes back to that question of have we got the evidence to make that recommendation?" (Field Worker, NSP)

"It wasn't just a group of people sitting down and writing a document, it really was evidence led" (Topic Expert, NSP)

"I think what is considered scientifically strong evidence is what NICE is briefed to consider. This is given the greatest weight" (Core Member, NSP/VD)

It is clear that the drive for information to be evidence led is an organisational priority. Previous research found that NICE community members felt that the evidence presented at committees was very clinical and this was viewed by committee members as being problematic because the focus of committees is on the development of public health guidance and not clinical guidance (Ursu et al, 2010, 13). The development of public health guidance needs to be different from other types of guidance such as clinical guidance and requires the involvement of a variety of evidence and not just statistics and facts. When public health guidance was added to NICE's remit, this was something that was understood by the organisation. Kelly recognised that evidence from other methods and designs would have to be appraised and that the data and evidence drawn upon in public health work would need to be broad and go beyond medical science to include the social sciences (Kelly et al, 2010). This created two immediate problems "a broader more epistemologically and methodologically diverse evidence base; and, multiple levels of analysis and operation" (Kelly et al, 2010, 1059) for NICE committees to include and consider. Taking this into account, it is no easy task to develop public health guidance as a multitude of evidence and information needs to be considered. Finding a balance of what type of evidence to include is challenging for NICE. There are examples of moral, ethical and social evidence which could

be included in PHAC meetings. These forms of evidence are typically qualitative and not based on clinical epidemiology (Upshur, VanDenKerhof and Goel, 2001). An inclusive model of evidence should be utilised by NICE which incorporates clinical and technical evidence but also social, moral and ethical. This inclusive approach may be better achieved in practice if NICE accessed a range of deliberative spaces, perhaps in the macro sphere, and included a broader type of committee member in their PHAC meetings such as social scientists and patients and not just topic experts or epidemiologists.

It is important to note however that one committee member involved in both processes felt that NICE was changing and had made improvements to be less driven by data suggesting that they were open to including other forms of information.

"I think you can get a bombardment of research and figures and stuff like that without actually maybe looking a little bit more at OK so what do we have out there at the moment? What's happening...it's very much based on facts, figures, research and the like...But they've really improved since that" (Core Member, NSP and VD)

The parliamentary data tells us that the common good is used more often in public arenas. Again, this is not surprising. Actors in public "appear to have a stronger pressure to make appeals to the common good" (Steiner et al, 2004, 30) and justify their positions with references that will appeal to the common good. Parliamentarians also want to get re-elected so are more likely to make appeals to the common good. As previously stated, NICE do allow the public to attend their PHAC meeting. There were members of the public in attendance but they were not always visible to the committee and there wasn't large representation. This may explain the lack of common-good in the NICE deliberation as committee members did not have to appeal to the public.

The publicity principle which was discussed in chapter two is interesting to re-visit given this finding. Gutmann et al (2004) argue that deliberation occurring within a deliberative

democratic process must be public. Habermas (2006) insists that publicity and transparency encourages good deliberation and legitimacy, however some see limits to the publicity principle. Publicity could change the dynamics of deliberation causing deliberators to provide reasons which they do not fundamentally believe or support. For example, public deliberation may influence participants to say what they think the public wants to hear in order for them to gain more support or approval (Chambers, 2006). This is not terribly democratic but may suggest why there is a higher frequency of reference to the common good in public settings. If more or less members of the public attended NICE meetings, this might possibly change the frequency of reference to the common good and is something which NICE might consider.

#### **5.7 Stories**

The final DQI measure to consider is story-telling. Chapter two discussed the importance of allowing other forms of communication into the deliberative democratic model. There are benefits to including a variety of deliberation into decision making such as story-telling, lived experience and rhetoric. Storytelling helps "deliberators to identify their own preferences, demonstrate their appreciation of competing preferences, advance unfamiliar views and reach areas of unanticipated agreement" (Poletta and Lee, 2006, 699). Stories can also provide meaning to clinical data and bring the numbers to life (Staley et al, 2016). In healthcare, lived experiences of patients and front-line workers are important to consider as these accounts bring an element of everyday life to decision making. Decision makers needs to be cognisant that the decisions they make ultimately affect real people and therefore experiences, stories and opinions need to be included in the process. Staley et al. (2016) found that the inclusion of patient statements helped committee members in NICE evaluate clinical and economic data as the statements offered a different perspective which was based on experiential knowledge.

Young (2001) argues that structural inequalities prevent particular groups (women, ethnic minorities, working class men) from engaging in deliberation and in deliberative democracy due to its prescriptive nature. Deliberative democracy requires participants to have skill in providing reasoned and justified arguments and have a certain degree of knowledge in the topic. The deliberation within NICE PHAC meetings has been described throughout this chapter as expert deliberation meaning one requires certain deliberative skill and understanding to be able to engage as an effective participant in the process. This can be described as being exclusive and prevents certain groups such as lay citizens and service users from being able to influence decision making because they lack the skills or resources to do so. Some committee members spoke about particular groups who they felt find it difficult to participate in the PHAC meetings such as citizens, front-line workers and service users. The comments below from committee members describe this well.

"But also the number of people and the set up, all those microphones, I mean I was terrified and I knew quite a lot about my project area. So I can imagine for a member of the public it would be very difficult unless they were particularly confident in person, and like I said good communication skills" (Topic Expert, VD)

"I'm thinking of some front-line workers locally, if they were to access that they might be a bit daunted by that...Just the whole formality might not be everybody's cup of tea" (Topic Expert, NSP)

By relaxing the norms of deliberative democracy to include story-telling, this might help other groups to better engage in decision making and feel more comfortable in deliberating with experts. Earlier versions of the deliberative democratic model did not include storytelling, it is therefore important to understand if story-telling is now being used in deliberation since there has been a call to relax the model (Dryzek, 2000). Story-telling is a characteristic of type II / macro deliberation. Given that the deliberation has so far resembled type I / micro

deliberation, it is anticipated that there will be few examples of story-telling in the NICE environment.

Table 5.8 displays the NICE vitamin D and NSP frequency data for reference to stories.

Coding was applied to speech acts where; a) stories were used as a justification for an argument; and b) when no stories were used. The table also displays the parliamentary data for the Switzerland plenary and committee studies for both the language and labor law deliberation. The data will be used to explore if the deliberative environment influences the use of story-telling as a justification for arguments presented and if different types of deliberators refer more to stories.

Table 5.8: NICE data, Swiss parliamentarians plenary and committee language and labour law data (percentage) – Stories

Sample	None (a)	Stories Used (b)
NICE Vitamin D	95.8%	4.2%
NICE NSP	100.0%	0.0%
Swiss Parliamentarians Plenary (Language)	70.0%	30.0%
Swiss Parliamentarians Committee (Language)	81.0%	19.0%
Swiss Parliamentarians Plenary (Labour Law)	90.0%	10.0%
Swiss Parliamentarians Committee (Labour Law)	96.0%	4.0%

There was a higher frequency of no stories (a) being used across both NICE samples. The data in table 5.8 shows there was a slightly higher frequency of stories being used in the vitamin D sample (4.2%) than in the NSP sample (0.0%).

Overall, the data in table 5.8 suggests that parliamentarians and committee members in an epistemic community rarely draw on stories to justify their position or argument. The NICE data is most consistent with the Swiss committee on labor law. Table 5.8 shows that the highest frequency of stories used were in a plenary environment regardless of the topic under deliberation.

The Swiss data is interesting as it highlights that more stories are told in plenary sessions held in a public setting than in committee sessions behind closed doors. Although NICE describe their meetings as committee meetings, they are not closed and the public are allowed to observe. This perhaps encourages a degree of transparency in the process. However, very few observers attended the PHAC meetings and this could explain why very few stories were used by committee members. Perhaps if more patients attended the NICE PHAC meetings this would influence committee members to refer more to their stories and experiences creating a very different deliberative environment. Including more patients in the PHAC meetings could help NICE produce better decisions as their experience and stories can bring a different layer of insight to the process that experts simply cannot provide. This means that decision made would potentially be more reflective of those directly affected by these decisions made.

Overall few stories were used as a justification by participants in the vitamin D sample and no stories were used in the NSP sample. Using a story to illustrate and justify an argument or a reason could provide an element of lived experience and insight to the deliberation making it less clinical. These guidelines do affect people's lives and their stories should be reflected in final guidance produced by NICE.

Throughout this chapter, it has been argued that NICE encourage committee members to use evidence based, factual information. This is very much in line with expert deliberation which is said to focus on technical judgements. It is not surprising that stories were not part of the formal 'micro' deliberation and that type I deliberation was more dominant. During interviews, committee members expressed that they could appreciate why NICE placed more emphasis on evidence rather than stories suggesting that it difficult to base important decisions on a story that isn't evidence based.

Two members involved in the NSP PHAC meetings recognised the challenges facing NICE to be representative and inclusive of all forms of evidence. These members also understood the tension surrounding the benefits of including type II discourses in decision making and being able to evidence experience, story-telling and rhetoric.

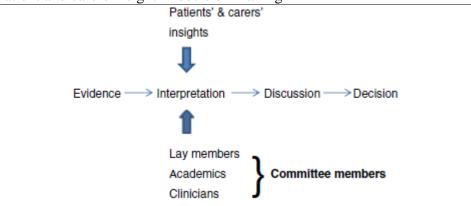
"I think the chair was very keen to hear about anecdotal things, you know, so I might have said I've had a service user ring me up and say blah, blah, blah, and listened to those stories but at the end of the day what goes down on print is around evidence" (Topic Expert, NSP)

"I think the difficulty for NICE is the stuff that sort of, people like me know from our practical experience in talking to people...And they can't really say well we spoke to people and (John) said this is what we needed to do. So, I can see their difficulties with that" (Topic Expert NSP)

Perhaps one way to overcome the difficulties with basing decisions around stories and lived experience is to not consider them as research evidence but rather experiential knowledge or insight which plays a role in the interpretation of research and in clinical judgements.

Information from patients does not need to function as 'evidence' in the same way as clinical and economic data and it should not to sit alongside or be weighed up against clinical/ economic data (Staley et al, 2016). Stories and lived experience then may be better understood as an "interpretive tool to aid Committee members in their evaluation and deliberation of the existing clinical and economic data" (Staley, et al, 2016, 12). This idea is displayed in Figure 5. This type of information is crucial for clinicians to consider in decision making.

Figure 5: Patient and carers insight in decision making



Source: Staley et al, 2016

The interview data also tells us that some committee members found the environment in which meetings took place quite formal. The use of microphones and layout of the room may have inhibited story-telling. Despite the lay-out being in a horse-shoe shape, committee members still sat opposite each other which could be viewed as oppositional rather than collaborative or participatory. Committee members who were involved in both the NSP and vitamin D process mentioned that the language and evidence used in the vitamin D process was often quite complex when compared to the NSP process. As a result of these conditions, story-telling might not have been viewed as being appropriate for committee members to use as a credible source of evidence due to the epistemic nature of the deliberative environment. The physical set-up was formal with the use of microphones which may have inhibited some individuals for engaging in the process and telling their story.

The data in table 5.8 tells us more about committee members. In this sample, committee members such as doctors, professors and clinicians rarely communicate using stories or type II deliberation. However, patients would ultimately tell these individuals about their experience and treatment so it is surprising these accounts were rather limited. Perhaps the experts and clinicians engaged in the process were no longer front-facing and did not have a current case load and this could explain the lack of patient stories. Furthermore, Gutmann et al. (1996) recommend that experts should tailor their expert language into ordinary language

in ways that others can understand. Perhaps NICE could encourage more use of type II deliberation so the deliberation becomes more relatable and understandable to other groups of individuals such as lay citizens and community members. In PHAC meetings, it would be interesting to explore if the participation of more citizens and service users changes the frequency of stories and other forms of communication being used. There is "empirical evidence to suggest that ordinary citizen often use personal stories to support their arguments" (Steiner, 2012, 67). Social scientists also draw upon qualitative accounts and lived experience when interpreting their own research and data. Given that there was little representation from ordinary citizens, patients and perhaps social scientists this may explain why there was little lived experience and story-telling in the deliberation.

Striking a balance is important in relation to the type of evidence presented. Type I and II deliberation should be included in health-care decision making. Two committee members interviewed appreciated the importance of balance in relation to including both type I and II deliberation in the process.

"...I think NICE, the work they do, if it's all clinician led that's not very constructive. I think brining in a multidisciplinary and community representative approach it gives the patient body and the wider health provider a voice without giving the individual patients that much of a voice" (Topic Expert, NSP)

"...the meeting I was at the other day, in Manchester, there was quite a lot of talk from the experts who were clinicians about, not just the results of trials, which weren't all that convincing, but the effect that treatment has on people's mental health and wellbeing. I think that's becoming more obvious when they bring in patient representatives. The committee gets a feel what it's like to live with the condition day to day" (Lead Reviewer, VD)

NICE need to consider where type I and type II discourse should be located in the deliberative process. Given that story-telling was rarely used as a justification by NICE committee members and that the environment wasn't set-up to allow this, other forms of communication might better placed in the macro spheres of deliberation rather shoe-horning it into the micro

process where it might not be all that relevant. This would be similar to Bachtiger et al's sequential (2009a) approach where story-telling and other forms of communication could be used at the start of deliberative process rather than at the later stages. The sequential approach is discussed in more detail in chapter two, section 2.3.3.

It may be that personal stories are better placed at the beginning of a decision making process (Steiner, 2012). If story-telling happens at the beginning and ordinary citizen use personal stories, NICE could explore how to better connect to the macro sphere. Deliberative forums such as the NICE Citizen Council could be better utilised with deliberation being linked into the PHAC meetings. A different option would be for NICE to connect with other macro forums. These suggestions will be explored further in chapter six.

Story-telling helps the socially disadvantaged to get a better voice (Young, 2000) and is important for increasing equality, enhancing representation and democratic legitimacy in decision making. It also brings a different perception and insight to the decision making process (Staley et al., 2016). Given that committee members identified that some types of participants would find it challenging or difficult to engage in the more formal PHAC meetings, NICE need to encourage the inclusion of other forms of communication at some point in the process to attract different types of voices. Clinicians and experts should also be encouraged to explore patient experience and bring this to the PHAC meetings. A different option may be for NICE to reconsider how lived experience, stories or type II deliberation is used in the decision making process. Rather than defining this information as evidence and weighing it up against economic/ clinical data, type II deliberation could be used to interpret that data.

From a deliberative perspective, story-telling should be included at least somewhere in the

deliberative process. However, balance is key and consideration should be given to where story-telling is best placed in the decision making process.

### **5.8 Conclusion**

The data has shown that the deliberation in NICE PHAC meetings was of high quality. There was a high level of respectful listening and also sophisticated justifications provided for arguments. There were low instances of interruption and foul language. These are typical characteristics of type I deliberation and what would be expected in micro conceptions of deliberative democracy. Overall, there was very little difference between the NSP and vitamin D samples suggesting that the deliberative process and deliberative quality was quite similar in both processes.

There was a good standard of quality deliberation in the NICE PHAC meetings based on the DQI but this may be as a result of a number of factors. The process was relatively closed in relation to participation. Participants came from a similar senior level medical background and likely had experience of engaging in formal deliberative processes. They were relatively respectful of each other and their positions. This meant that committee members could "subscribe to a common discourse" (Dryzek, 2011) and this encourages stabilization in a network. This stabilization could be viewed as concerning for NICE. A stabilized discourse will ultimately "serve some interests and marginalize others, highlight some concerns and downplay others" (Dryzek, 2011, 125). This means that critical questions, perhaps from citizens, patients and other experts, are ignored (Dryzek, 2011). If a network "shuts out contending discourses, then it risks becoming progressively illegitimate with time, as well as ineffective in problem solving" (Dryzek, 2011, 126).

A deliberative process must also be democratic (Dryzek, 2011, Blowers, Boersema and Martin, 2005) meaning that while quality is important, the process must also be inclusive and it must encourage unconstrained dialogue. While the DQI results would suggest that participants were able to engage in relatively free, unconstrained deliberation, inclusiveness might be questioned. There was little citizen or patient involvement. This may explain why a common discourse was evident. The majority of committee members were from the health sector holding relatively high professional roles or defined as experts in the topic. For democratic deliberation to be achieved, participants should be from different demographic, social and geographical backgrounds (Blowers et al, 2005). This did not seem to be the case in the NICE committee meetings. There were few patients, carers or citizens engaged in the process. This is also true for other experts. Most of the experts had a medical background meaning that social scientific experts were not well represented. This might explain why participants were relatively agreeable with each other and were respectful of each other's positions because most were from the same background. All participants seemed likeminded individuals. Deliberation amongst like-minded people would not be contentious or disrespectful.

The data confirms that expert deliberation is occurring within the NICE committee meetings that were sampled. Expert deliberation is not driven by maximum inclusion and participants are often selected for their competence and expertise in a particular area (Moore, 2016). This is a similar situation to the selection of committee members in NICE. Expert deliberation is based on deliberation amongst a small group of specialists. In the case of both PHAC meetings, the majority of participants were topic specialists / experts. The data also confirms that the NICE PHAC meetings closely resemble micro conceptions of deliberative democracy because membership was exclusive and the environment was relatively formal and structured.

Type I deliberation was most commonly used in the PHAC meetings and there was few instances of type II deliberation such as story-telling.

It is evident that committee members can be involved in a number of PHAC meetings at the same time and over different periods of time. This suggest that committee members can also become 'experts' in this particular deliberative process as they can develop experience, skill and knowledge by simply engaging in the process. Those committee members ultimately know what to expect and what the deliberative standards are so it is not surprising the quality is relatively high. NICE also inform members what is expected of them prior to meetings. The types of individuals involved in the PHAC meetings would also be engaging in similar deliberative processes or forums separate from NICE as part of their professional roles. Those individuals might also be defined as expert PHAC members due to this experience.

It is not necessarily a bad thing that expert deliberation is occurring in NICE. Experts are required, particularly in healthcare and networks, to provide a level of knowledge and expertise that others just simply do not have. It is important that this level of decision making is of high quality. However, experts do not always have all the required information or evidence and we should not assume that "deliberation will be better informed and public policy better served if legislators follow those who are generally presumed to be knowledgeable about a topic" (Mucciaroni and Quirk, 2010, cited in Steiner, 2012, 63). Further to this, if NICE are going to rely solely on experts then they should at least include a range of experts with different backgrounds and not just those medical experts / professionals.

NICE need to be better at is broadening out their scope in terms of who participates in the micro sphere, encouraging more 'everyday talk' (Mansbridge, 1999) in the macro sphere and try to strike a healthy balance between incorporating micro and macro deliberation into the

development of public health guidance. From the interview data, it can also be argued that the PHAC process is quite insulated from the macro process and therefore might explain why the deliberation was quite stable. There was little input from lay citizens, carers or service users and deliberation was largely dominated by experts. This means that shared understandings and common discourse could emerge that was never really contested by others from different backgrounds or positions.

To conclude, the deliberative quality in the NICE samples was relatively high and can be described as expert deliberation occurring in a micro conception of deliberative democracy. Although the quality is high, it may be that NICE are not particularly democratic and fail to meet democratic standards such as transparency, inclusion and representation. Given that the deliberation was not very democratic, connecting to the macro sphere could be beneficial to NICE and this will be explored further in chapter six.

# **Chapter 6. Macro Deliberation Occurring Outside NICE PHAC Meetings**

### 6.1 Introduction

This chapter explores how networks such as NICE deliberate at a macro level and if they combine micro and macro deliberation. Micro deliberation is often defined as rational, justified, formalised discussion between a small group of like-minded individuals who come together to agree on an agenda, reason and argue and settle on an outcome (Hendriks, 2016). Macro deliberation is informal, spontaneous and inclusive of wider public dialogue. Macro deliberation is necessary to allow "new issues to emerge on the agenda" (Chappell, 2010, 299). However, micro conceptions of deliberative democracy are criticised for being too formal and exclusive. Macro conceptions are criticised for being too informal and lack necessary structure to form decisions. Both approaches need to be combined to overcome these problems outlined above. As the previous chapter indicated, NICE PHAC meetings closely resemble micro conceptions of deliberative democracy where type I and expert deliberation is used by committee members. This chapter examines a type of deliberation that is quite different from those discussed in chapter five. The deliberation described here should be loose, informal, inclusive of face-to-face meeting but also of wider public debate involving the media, associations, patients, citizens and networks.

Firstly, this chapter will establish if macro deliberation occurred outside PHAC meetings. It is essential to ascertain if this macro deliberation was linked to the micro deliberation because the PHAC meetings observed were largely exclusive. There was limited representation from particular groups of individuals such as patients, citizens and front-line workers. Deliberation was dominated largely by experts and professionals from the medical sector. Extending the deliberation into wider spaces could make the guidance process more inclusive and

representative of other discourses as this is where citizens and patients for example are likely to participate in deliberation.

Interviews were conducted with eleven individuals who were committee members in PHAC meetings; committee members were tasked with developing public health guidance on two different topics (needle and syringe provision and vitamin D guidelines). During the interviews, committee members were asked to describe any deliberation which took place outside the NICE PHAC meetings in order to assess the type of deliberation occurring. Overall, some wider discussions seemed to be taking place outside the vitamin D and NSP processes. However, committee members did not view this as being of any real significance or importance. The nature of discussion was informal and occurred between those close to the committee member such as other colleagues. The discussions took place when the opportunity arose and was not actively sought. It was convenient, face-to-face and private. While these are considered elements of macro deliberation there were some elements missing such as wider public debate spanning across a range of forums and spheres. This is also a crucial element of macro deliberation.

Secondly, using data from the interviews, the chapter will address if macro deliberation was connected in any way to the micro deliberation occurring in the PHAC meetings. The chapter will discuss if governance networks such as NICE have the potential to combine micro and macro deliberation. This combination is important so different discourses and participants have the potential to influence each other and the outcomes of decisions. Thirdly, the chapter will conclude by outlining ways in which NICE procedures could be amended to improve how they combine micro and macro processes drawing upon the concept of coupling and bride-builders. Coupling (Hendriks, 2016, Mansbridge, et al., 2012, Papadopoulos, 2012) is a concept which can be used to integrate deliberation occurring in different spheres and is

therefore relevant to NICE and networks. Bridge-builders are associated with betweeness (see chapter four, section 4.3.1) and tells us if an individual makes connections between those who are not directly linked to one and other. Bridge-builders can be used as conduits between the micro and macro sphere to ensure they are better connected and spread. Committee members with a research background for example may be ideal bridge-builders as they have skills in seeking out different views and opinions and can link those views back to the formal network. They can aid coupling.

### 6.2 Macro Conceptions of Deliberative Democracy and Type II Deliberation

Habermas (1996) argues that macro deliberation takes places in informal spaces in society where communication is spontaneous. Due to this spontaneity, it is unpredictable and can occur in a range of communicative spaces including small face-to-face discussion to protests. Given this description, it is easy to understand why it is quite difficult to capture and measure the deliberation occurring in macro conceptions of deliberative democracy because of the wide scope.

While decision making should be the goal of micro conceptions of deliberative democracy, opinion formation of those engaged in macro spheres should be the goal in macro conceptions (Hendriks, 2006, Habermas, 1996). Membership is large and because of this macro conceptions are less structured and inclusive (Hendriks, 2006) where looser types of communication emerge including story-telling, rhetoric, experiences and humour. This is similar to type II deliberation (Bachtiger et al, 2009) as other forms of communication are present in type II. Macro conceptions of deliberative democracy and type II deliberation can however be accused of concept stretching (Ercan and Dryzek, 2015) as they do include many types of deliberation that some would class was unreasoned or even non-deliberative

(Chappell, 2010). However, the core ideals such as respect and reasoning are characteristics which should still be present in both macro conceptions of deliberative democracy and type II deliberation.

Macro conceptions help overcome the scalar issues associated with micro conceptions of deliberative democracy (Parkinson, 2006) because they are generally more inclusive and occur in a range of less formalised spaces. This is important for deliberative democracy and networks such as NICE as it is impossible to directly include all those affected by decision making in their guidance development processes. Macro conceptions of deliberative democracy are more tolerant of other forms of communication which can help encourage a diverse group of participants to engage in deliberative processes and decision making. Type II deliberation aims to move away from abstract ideals to accommodate institutional design and social inequalities because it is more flexible than type I deliberation. Therefore, the idea of coupling with macro spheres of deliberation could help NICE and other networks become more inclusive, diverse, representative and legitimate. It could also help them make better, informed guidance. It may be the case however that NICE chooses not to engage that often in macro spheres are they are less formal, messier and more challenging to control.

Drawing upon the interview data, the nature and style of deliberation occurring outside the PHAC meetings described by committee members will now be discussed.

### 6.3 The Nature and Style of Discussion

Committee members from the vitamin D and NSP PHAC meetings were asked if they consulted other organisations/individuals about the guidance process they were involved in.

Three initially said they had not engaged in any discussions about the topic outside the PHAC meetings and provided reasons for not doing so.

One committee member involved in both the vitamin D and NSP process felt that speaking to others would make them less independent as a member.

"No I haven't (spoken to other organisations). I would be a bit concerned about doing that. I would worry that maybe I might not be as independent if I was starting to do that" (Core Member, VD / NSP)

Two of the three committee members discussed who said that they did not speak to others felt they had enough knowledge, experience and expertise to offer.

"No I didn't, but I think that's because I feel I'm drawing on what I've learned over the years...I think we've had lots of experience of trying to implement so I think I'd drawing on experience talking to lots of different bodies but I didn't proactively go and do anything more during this process" (Topic Expert, VD)

"I didn't specifically for the guidance but I already had in place quite a lot of it, I've done a lot of research in the past. That was already in place so I didn't need to" (Cooptee member, NSP)

This was an area which required more probing during the interviews. The two members quoted above did in fact speak to others but they did this very informally and did not recognise the significance of this when questioned about wider deliberation. This is reflective of the majority of committee member descriptions and is in line with the definitions of macro deliberation – i.e. loose, ongoing and informal (Chappell, 2010).

A further eight committee members said that the topic of the guidance they were involved in would come up in general conversation but they did not pro-actively go out to speak directly about the guidance to others. NICE do not follow Chatham House rules in meetings, however the NICE team will update committee members on what information can and cannot be

shared out with the PHAC meetings. Perhaps this prevents committee members from engaging in deliberation outside meetings as they are unsure about what they can talk about with others. External discussion was however spontaneous and this is what would be expected of deliberation occurring in the macro sphere. The comments below from two NSP committee members highlight the spontaneity of the discussions taking place. The tone is relatively throw-away and appears to be of not much great significance to the committee members.

"It might come up in conversation, oh I'm doing this and there's that new guidance that's coming out and I know it's going to recommend this and we're not currently doing...just giving an insight as to what's likely to come up" (Topic Expert, NSP)

"I think it's well publicised and I think panel members probably chat to people and, you know, I chatted to people about general topics. (Topic Expert, NSP)

A total of ten out of the eleven committee members who were interviewed said they engaged with others outside the PHAC meetings. This means that the majority of committee members did engage in some form of macro deliberation outside the PHAC meetings which is positive given issues with the deliberation occurring in the PHAC meetings.

### 6.4 Reasons for Engaging in Discussion outside the PHAC Meetings

Committee members were asked to elaborate on why they consulted others. For one NSP committee member speaking to others was part of their role in the PHAC meeting. Their role as a field worker was to gain an understanding of the experiences and opinions of those not directly involved in the development of the guidance, but who would be affected by it (the workforce and service users) and to present this information to the committee. This particular member said that they consulted with over 60 separate individuals as part of their wider discussions. It could be argued therefore that this member acted as a bridge-builder

between the micro and macro discussions which were taking place as they transmitted discourse from one deliberative space to another deliberative space. Bridge-builders play a role in the spread of deliberation across the public and policy domain and act as conduits of the discussion.

These deliberative occurrences described by the field worker are a good example of macro deliberation. However, this particular committee member had a clear agenda which was to understand others' perspectives. The discourse was probably more structured than what might be expected of macro deliberation. The discussion was not as spontaneous as the type of discussion that was described by other committee members. Here, deliberation would have taken place at a set time and date, questions would have been pre-set and the nature of the discourse would have been driven by the field worker. This could then be described as an example of micro deliberation. Having said that, the committee member explained that the whole purpose of fostering external discussion was to gather opinions and feed those back to the committee which is an aim of macro deliberation. This is an example of how macro deliberation can still be structured but less formal and integrated into micro processes.

"...We are a research company, that is our bread and butter really (speaking to others)...whether it's professional, people using the service, at any level we could be speaking to people. So I think it's always really useful to get the opinions of people either using or delivering services" (Field worker, NSP)

It is unclear if every guidance development process has a committee member carrying out this function, however having a dedicated committee member scoping out opinions and discourses external from the PHAC process could help better integrate micro and macro deliberation. A fieldworker might for example tell service users about potential changes to guidance, ask how they feel about that change and how the change might affect them. The fieldworker could subsequently take that information back to the PHAC meetings.

Opinion formation should be the primary function of macro deliberation (Chappell, 2010, Hendriks, 2002, 2006). It is different to the aim of micro deliberation which tends to be decision making. The majority of committee members who spoke to others did so for the purpose of clarifying their own position and information before presenting this to the committee, essentially solidifying their opinions and arguments. This occurred in both the NSP and vitamin D processes. Committee members often used others external to the PHAC meeting for reassurance and as a sense checker to help formulate their opinions on the relevant topic. The comments below provide further insight into the reasons why committee members consulted with others outside the PHAC meetings.

"...it's quite nice to get some reassurance that what I'm thinking isn't unusual or if it's unusual, what is it about it that's unusual, and trying to put what I think into context with other practitioners" (Topic Expert, NSP)

"I've spoke to them about drop boxes and stuff, just to clarify because I obviously don't know 100% about everything...So kind of getting a bit of background advice" (Community member, NSP/VD)

"Yes I did (speak to others). We had some reports that were put together by the primary care trust...and it looked quite valuable so I got in touch with the primary care trust to get more information" (Research, VD)

"I did talk to a couple of people locally and when things did come up in the debate I did sometimes contact the local pharmacy committee...But really that was sort of to check out my own perceptions basically" (Topic Expert, NSP)

One external contractor interestingly commented that they were not experts in the topic area and therefore had to seek out the 'experts' to understand the topic better. It is clear that experts play an important role in the micro committee process as discussed in chapter five but also in the macro sphere as described by this committee member.

"We often do that to plug the gaps in our models...And we're economist, we're not experts on vitamin D...and we had to speak to them to understand what the whole promotion was made up of" (Health Economist, VD)

In terms of centrality (see chapter four, section 4.3.1) topic experts clearly play a core and central function in the micro and macro sphere. They do appear to be more influential than perhaps other types of committee members. This is a key reason why the deliberation has been largely classed as expert deliberation. Experts are continually consulted throughout the whole process of guidance development with limited inclusion of other groups of individuals. This would however be expected in an epistemic community but this is not how NICE necessarily define themselves.

Despite a low frequency of story-telling in the PHAC meetings coded in chapter five, committee members said they consulted with others to hear stories, experiences or testimonies and would use these as evidence in PHAC meetings. The examples below provided by committee members are all forms of communication defined as type II deliberation and often found in the macro sphere therefore there may be some integration between macro and micro deliberation in relation to story-telling. The macro deliberation occurring outside the PHAC meeting may compensate for the absence of this in the committee meetings. Committee members from both the vitamin D and NSP process expressed that they often presented their own or other individuals experiences to the committee. This however was not reflected in the samples of data in chapter five.

"Yes certainly stories and anecdotal evidence because obviously I talk to our pharmacists and we've got a Needle Exchange Coordinator" (Topic Expert, NSP)

<sup>&</sup>quot;It was more experiences. It was gathering the experience and opinion, sort of expert opinion or professional opinions on those directly involved in the commissioning or delivering services" (Field Worker, NSP)

<sup>&</sup>quot;Yes we did do some stories and experience from a website...there had been some evaluations done and women's opinions so quite a few of those experiences went into the systematic review" (Lead Reviewer, VD)

"It's more experience I think" (Topic Expert, VD)

"Just expertise about vitamin d... but also just my experience with dealing with parents or dieticians, parents whose child has either got rickets or vitamin D deficiency" (Topic Expert, VD)

# 6.5 Speaking with others outside the PHAC Meetings

A broad range of individuals/organisations were consulted by committee members about the topic guidance they were developing. However, because of the spontaneous nature of the deliberation, it was difficult for committee members to provide an accurate number of the different individuals they might speak to. Given the scale of macro deliberation, it might not be realistic to expect deliberators to provide an actual figure. Members of the NSP process were better at recalling specific groups and individuals they consulted with compared to those committee members in the vitamin D meetings. In the NSP process, it is clear that the bulk of the wider discussions were conducted by the field worker as they came into contact with a range of different organisations. Overall, the field worker engaged with needle and syringe providers in the community including pharmacists and counter staff managing distribution. Specialist organisations, charities and commissioners working specifically in the field of addiction were also contacted by the field worker. Other NSP committee members consulted with health practitioners, substance use researchers and people local to them. In terms of density, the size of the argument pool was quite broad due to the diverse range of individuals involved. However, it could just be as easily argued that those different individuals may have had the same opinions and perspectives and so the argument pool might not have been as diverse.

"Yes, so providers of needle and syringe programmes came from, it was (NAMED ORGANISATIONS), some of the main providers...there was a lot of pharmacy providers attended the group. We had charities delivering the programmes...pharmacy workers so both pharmacists and counter staff...Then there was all the commissioners as well...we spoke with the (NAMED ORGANISATION)" (Field Worker, NSP)

"So I think the people I come into contact with mostly are pharmacists and substance use researchers, probably health practitioners, but yes, I think I flagged it up to a couple of people through that" (Topic Expert, NSP)

"I told people locally here" (Topic Expert, NSP)

Overall, the deliberation in the NSP process was described by committee members as quite private between colleagues rather than public debate occurring in wider spaces inclusive of media, associations and networks. This public element was certainly lacking.

In the vitamin D process, committee members explained that they consulted their clients and service users who they were working with as part of their professional work including children, patients, research teams and staff in hospitals. Committee members clearly use their own networks to gain the data and information that they require.

"Well just through my normal work...It's just carrying on working with parents and children and writing up and doing research for writing articles" (Topic Expert, VD)

"Occasionally in the committee people will say have your tried speaking to so and so and such hospital because they've done a study on this and they might have some data" (Health Economist, VD)

Again, what is described in the vitamin D process lacks the inclusion of wider public dialogue and is more like private and convenient discussion. Committee members often consulted those who they had direct contact with and who were in their reach such as colleagues, clients and service users. The deliberation was spontaneous, informal and quite loose and these are characteristics of macro deliberation. However, there are clearly elements missing. Macro deliberation should occur over space and time, including wider public dialogue taking place in pubs, cafes, and legislatures, in the media and in civil society groups (Chappell, 2010, Hendriks 2006). It is aimed at formulating opinions rather than decision making. What has been described by committee members was more convenient, face-to-face, private deliberation between close colleagues and professionals. Macro deliberation does include

face-to-face meetings but it also "encompasses communication where there is a greater distance between participants" (Chappell, 2010, 300) and this was not described by committee members. Wider civil society still appears removed from the process. Committee members were also not aware of the significance of these wider discussions and how they might be linked to the micro deliberation taking place in the PHAC meetings. As a result of this, the deliberation which was occurring outside the PHAC meetings could simply be described as an extension of micro/expert deliberation as it mainly took place between topic experts and similar colleagues and professionals.

## 6.6 Integrating Macro Deliberation with the Micro

So far, the chapter has illustrated that some instances of macro deliberation did occur outside PHAC meetings and that there were elements of macro deliberation present. Crucial elements were however missing. The second part of this chapter will ascertain if this deliberation was integrated with the micro deliberation in PHAC meetings.

Deliberation should be meaningful; it should have a purpose or an aim such as decision making, setting an agenda or shaping opinions. Other than the field worker described earlier in this chapter, one other committee member involved in the NSP process provided a good example of how they linked those wider discussions into the micro PHAC meetings and made them meaningful.

"I was at conferences and ideas cropped up and people talked about stuff and you bring that to the committee when you're next at the panel" (Topic Expert, NSP)

The example given above has more flavour of the wider public deliberation that is crucial to macro deliberation. This is because conferences usually provide space and time for delegates

to reflect and deliberate with each other in larger groups rather than private, one-to-one discussion. This might be done between delegates face-to-face at the conference or through social media reaching wider audiences. The member expressed that they felt they had also influenced others external to the process to participate in the NICE process by encouraging individuals to comment on the draft guidance and register as stakeholders. This allows wider groups to review the guidance and provide comments and opinions which are considered by the committee. This process occurs in all guidance development processes and is an opportunity to extend the dialogue to include wider audiences. What is missing however is the opportunity for those stakeholders to engage with each other and deliberate more widely in a public forum about the guidance or the comments. It is still limited to a small group of experts.

"I think I did encourage a couple of people to actually respond to consultation" (Topic Expert, NSP)

In the quote below it is also interesting to note that the same committee member was "cautious" about what they said to people externally perhaps suggesting that NICE may not encourage wider discussions taking place outside the micro forum; that discussion should remain private or confidential. This would certainly prevent dialogue being linked with the wider public domain. NICE have often been criticised in the media for their decision making, particularly around rejecting the supply of certain drugs. This may be the reason why they are keen to contain deliberation and opportunity for wider public debate.

"I was a bit cautious about what I said I suppose but I asked some people questions certainly and I spoke to people at conferences." (Topic Expert, NSP)

However, in the situation described by this topic expert, we see both the micro and macro spheres influencing each other which is positive.

A further theme emerged from the interviews about the difference between micro and macro deliberation and is related to the argument presented in this chapter about NICE deliberation just being an extension of micro/expert deliberation. Macro deliberation is characteristically different to micro deliberation, however rather than being viewed as separate; they should be viewed as being on a spectrum. It is relatively straightforward to distinguish the different types of deliberation when they are occurring at the furthest ends of the spectrum. However, it is more difficult to distinguish the boundaries i.e. when one actually ends and another begins. The lines are blurred. This occurred in the NICE PHAC meetings and a good example of this blurring was discussed with a committee member involved in both the vitamin D and NSP process.

One contractor explained that committee members might raise an important issue during the PHAC meeting that requires further exploration. Since the meetings are time constrained, it would make sense that this 'following-up' occurs outside the formal micro processes. What is not very clear here is if this is just another extension of the micro deliberation between a group of experts or if this is an example of macro deliberation starting outside the micro process.

"I mean we certainly contact other individuals. Often its members of the committee itself who kind of raised a key point...so we'll often have then an off-line discussion with them" (Health Economist, VD)

Similarly, a topic expert involved in the NSP process explained that they often consulted with others to try and find out more about a topic or to get a bit of perspective. Again, it is not clear if this deliberation is taking place outside the PHAC meeting in the wider sphere across time and space inclusive of different individuals or just during breaks between the same expert committee members.

"By being involved in the committee it encourages you to go and talk to people about the sort of topics that are there and find out more and I always find really useful when I go to a meeting to have a chat with somebody why I wasn't entirely clear about a topic or I wanted to get a bit of perspective" (Topic Expert, NSP)

Understanding the blurring is important because it illustrates the challenges associated with identifying when micro deliberation ends and macro deliberation begins and how they then might be linked. Despite a few distinct examples of macro deliberation being linked to the micro, the deliberation described by committee members could be defined as an extension of the expert deliberation occurring in the PHAC meetings as it lacks certain crucial elements pertinent to macro deliberation (spontaneous, wider public dialogue inclusive of a variety of spaces). It also seemed to occur between the same type of individuals or those involved in the close-knit group of committee members.

Examples of combining micro and macro deliberation were relatively limited. Only two out of the ten individuals who were engaged in some form of macro deliberation connected this to the micro deliberation suggesting this was a minority occurrence. More of this interaction between the micro and macro should be encouraged. This could help NICE overcome some of the issues with representation and exclusivity because the deliberation would potentially reach more individuals. Greater interaction occurring in the macro sphere could increase the diversity of voices and perhaps the inclusion of those voices which are absent from the process such as citizens, patients and front-line workers. NICE clearly have the foundations to support the integration of micro and macro deliberation as there are some examples of this already occurring but that needs to be strengthened. How NICE and other networks might achieve this now will be addressed.

### 6.7 Can Governance Networks Combine Micro and Macro Deliberation?

There were some instances of macro deliberation occurring outside the PHAC meetings however it rarely took place across time and space; it was private, convenient and essentially serendipitous. There were also limited examples of these instances being integrated with the micro deliberative fora. It may be the case that NICE do not want to engage in the macro sphere as it is potentially difficult to control. There is still opportunity to foster and encourage a connection however through various techniques in a controlled way. Coupling, using bridge-builders, and hosting less formal deliberative events in the macro sphere will be discussed as solutions which NICE could adopt in order to better integrate micro and macro deliberation. Three things are clear: 1) micro / expert deliberation is occurring in the PHAC meetings; 2) there are elements of macro deliberation occurring outside those meetings; and 3) both need to be more formally integrated.

### 6.8 Combining Micro and Macro Processes: Potential Solutions for Networks

Due to social complexities, barriers and inequalities, it is challenging to include all those affected by decision making in quality, meaningful deliberation. These challenges were observed in NICE. For example, the PHAC meetings were dominated by experts and other professionals who would typically engage in such processes. The process also lacked the inclusion of different groups of individuals such as citizens, front-line workers, service users and patients. This means that some quangos, like NICE, find it practically challenging to overcome the problems with institutionalising deliberative democracy. A number of solutions will be discussed next which could help NICE address these challenges.

Coupling has been recently used in debates focusing on linking deliberative systems (Hendriks, 2016, Mansbridge et al, 2012, Papadopoulos, 2012). Given that there was very little linkage of the micro and macro deliberation occurring in the PHAC meetings observed, this concept would be relevant for NICE. Coupling with different spheres could help NICE tap into more deliberative forums; potentially reaching more diverse participants in their own environment. Coupling could therefore help NICE overcome the issues with scale (Parkinson, 2004) as they could link with more deliberative spaces which would give them access to more voices. Consequently, this means that more individuals are potentially included in the decision making process and that those individuals can participate in spaces and forums where they feel equal.

Coupling can be applied to strengthen the connections between micro and macro deliberation. There are different types of coupling – tight and loose – and de-coupling. De-coupling occurs when parts of a system are so disconnected that "good reasons arising from one part fail to penetrate the others" (Mansbridge et al, 2012, 23). Participants ignore the positions and reasons generating from of each part of the system. This is clearly not optimal or effective for deliberation. When linkages are too tight "individual sites risk co-option" (Hendriks, 2016, 44) and lose their self-corrective capacity. A healthy deliberative institution inclusive of micro and macro deliberation at different points of the deliberative process requires loose coupling. Loose coupling is the normative ideal where different parts of an institution are loosely coupled so that they can accept the ideas and reasons emerging from other parts through the 'processes of convergence, mutual influence and mutual adjustment" (Mansbridge et al, 2012, 23). A loosely coupled group of institutions and practices together perform three functions "seeking truth, establishing mutual respect, and generating inclusive, egalitarian

decision making" (Mansbridge et al, 2012, 22). Loose coupling should therefore be the aim for NICE in order to strengthen the link between micro and macro deliberation. However, something more formal is required for NICE at this stage because existing links, if any, are too weak.

It is not fully understood yet if coupling could be organic in networks or if this is something which requires activation or steering (Hendriks, 2016, 46). There are some examples of coupling occurring in the PHACs observed. The instance described by the topic expert who discussed guidance at conferences and brought this back to the PHAC meetings has some elements of loose coupling. This is because deliberation from one sphere was shared with another sphere. Coupling in this manner could help NICE overcome the issues with institutionalising deliberative democracy. It can help NICE reach a number of different voices and address the scale issue. Coupling can encourage participants who do not normally engage in formal processes to participate in less formal ways helping NICE address the participation problem. NICE can couple with other deliberative spaces so that individuals feel comfortable participating in a process where information can be pitched at the appropriate level. This would further address the issue of inclusion.

Instances of loose coupling in NICE were limited but could potentially be developed further if NICE adopted a more active approach. Hendriks argues that from time to time organisations will need some aid to link different sites (Hendriks, 2016, 47) through designed coupling and this may be required for NICE and networks more broadly.

Designed coupling is a mechanism which aims to formally link disconnected sites (Hendriks, 2016, 47). One could argue that the PHAC meetings and the macro sphere were largely disconnected due to the lack of integration between the micro and macro deliberation. There

was also more examples of micro-type I deliberation than macro-type II deliberation in the overall deliberation. Designed coupling could ensure that more equal weighting is given to each deliberative sphere within the network as they would be formally linked. This would help overcome the problems with inclusion. All types of deliberation should be given equal weighting through coupling due to the different deliberative spheres being linked.

PHACs could be formally coupled with the NICE Citizen Council to enrich the committee's deliberation by "broadening the diversity and quality of public perspectives on a given issue" (Hendriks, 2016, 49). The Citizen Council provides NICE with public perspectives on moral and ethical issues that NICE need to take into account when producing guidance. The Council however does not input directly into individual guidance but could do so through designed coupling. Given that the general public were not particularly well represented in the PHAC meetings observed, this is one way in which NICE could enhance representation, increase citizen engagement and at the same time link macro deliberation with the micro. This would also help better institutionalise the core norms of deliberative democracy. Citizens engaged in the Council could transmit ideas and deliberation discussed in NICE to the wider sphere where they also frequently participate but also bring those discussions back to the Council and to the PHAC process. The aim is essentially to get different deliberative spheres engaged, connecting and influencing each other.

# 6.8.2 Bridge-Builders

Another way of achieving designed coupling is through the use of bridge builders who can act as conduits of deliberation. There were clearly committee members who played the role of a 'bridge-builder' between the micro and macro deliberation. Those who pro-actively consulted with others regarding the development of the guidance outside the PHAC meeting,

and who crucially brought that deliberation back to the PHAC meetings, can be defined as bridge-builders. Bridge-builders could be used to actively couple different deliberative spaces as they would play a role in a variety of spheres transmitting deliberation between each space.

In NICE, there were a few individuals who acted as bridge-builders. These included the field worker who was commissioned to conduct research for the PHAC meetings and a topic expert who had an academic professional role outside the PHAC meeting. Researchers and academics may be more suited to this role rather than senior level medical professionals. Researchers are often on the front-line exploring ideas, views and opinions and the impact that change has. NICE might want to actively recruit more researchers and academics that have a specific role to engage in macro deliberation outside the PHAC meetings and bring this back to the more formal process and vice versa rather than senior level topic experts.

NICE PHAC meetings suffered from representation and inclusion issues. There was limited representation and inclusion of certain groups of individuals such as citizens, patients, carers and service users in the meetings observed. The NICE PHAC meetings in terms of demographics were relatively homogenous and as a result the deliberation was largely weighted towards expert deliberation. The comment below from a committee member describes the demographic of their PHAC meeting suggesting that a more equal weighting of deliberators and their discourse is required.

"I think that there are many doctors, consultants and professors and commissioners on the groups, but maybe more nurses and staff from shop floor level should be include...giving a rounded view...I still think it's very top heavy with professionals and professors and medics and things like that, which obviously you've got to have a certain balance of it" (Community member NSP, VD)

Through designed coupling with the council, NICE could achieve a more balanced discourse that is not as stabilized. The council could provide committees with an "opportunity to hear

from a sector of the community" that committees "often struggle to reach and thus represent" (Hendriks, 2016, 51). This could help NICE overcome issue with representation and inclusion as different sectors of the community are engaged in the process. Further to this, designed coupling appears to encourage "elites to deliberate with a broader public constituency in mind and engage in arguments beyond the concern of their colleagues" (Hendriks, 2016, 52). This is important for public health which potentially affects large and varied populations and also for epistemic communities tasked with decision making.

Coupling in this manner can help NICE better connect micro and macro deliberation as one can hear from each other and encourage the cross-fertilisation of discourses between each sphere. Coupling can also support NICE to better institutionalise deliberative democratic norms as coupling can have an impact on inclusion, representation and accountability. It could also help them form better outcome through diverse deliberation.

There was very little formal interaction between committee members and those engaging in wider public dialogue such as citizens, patient, carers and service users. There is a role for the chair of PHAC meetings to better facilitate discussion between committee members and the NICE Citizen Council in a new kind of deliberative space. Committee members might be encouraged to attend council meetings and talk face-to-face with citizens. In a case where a mini-public was formally integrated into a legislative committee, Hendriks (2016) found that this had a positive impact on committee member's perception of citizens' knowledge and skills. This could also be the case for NICE committees if they are formally coupled with the Citizen Council. For NICE, it might be more effective if tight coupling was embedded where a more formal arrangement is made to connect the committee and the citizen council so that there is clear and formalised interaction between the different spheres.

Designed coupling can offer some minimum procedural guarantees to formally link relevant parts and participants in deliberation and this guarantee could make the NICE guidance development process more democratically deliberative as coupling would be formally embedded in the process. PHACs already have access to a council made up of representative citizens which it can be coupled with rather than re-inventing something totally new. This may make coupling easier for NICE to formalise in the first instance with a view to coupling with other wider deliberative spheres. It may also inject a new remit into the Citizen Council which has been operational since 2002.

NICE could take small steps to encourage more public dialogue through "using social media" to connect the broader public with face-to-face deliberative sites" (Hendriks, 2016, 47). This somewhat already occurs through the stakeholder comments function where stakeholders submit comments on draft guidance which are considered by the committee. However, having a more formal process might make this more effective and accountable. For instance, stakeholders could be invited into this review process so they can engage in face-to-face deliberation. This process would attempt to link deliberation occurring in the macro sphere with the deliberation that took place in PHAC meetings to formulate the guidance. It could encourage dialogue between wider audiences and allow the PHACs to be scrutinised or challenged if they decided to reject certain comments. Committee members would need to provide justifications and reasons for doing so to those outside the formal PHAC meetings. This is important for transparency. NICE may wish to encourage the media to attend PHAC meetings so the general public can be updated on changes to popular guidance and to encourage wider debate about topic specific issues. While greater face-to-face deliberation would be the most preferred option for NICE to consider, they could use social media platforms to generate debate on topics they are deliberating and review the comments during PHAC meetings in real time if time is set aside.

Coupling seems beneficial not just for NICE but for networks more generally and it can help them better institutionalise deliberative democracy. By coupling with other deliberative spaces in the macro sphere, networks can include a range of different individuals in their decision making processes rather than just professionals and experts. Participants likely to engage in macro spheres include "social movements, networks, NGOs, activists and interest groups, corporation, the media and opinion leaders" (Hendriks, 2006, 500). This could help networks overcome the issues with scale as more individuals can be accessed. Coupling would help address inclusion issues as individuals are accessed in their own environment in less formal ways. It would address the issues with participation because if networks are more visible in these different deliberative spaces then more individuals may actually decide to participate. Networks cannot assume that interested individuals will come to them. They have to be more visible and active in other deliberative spaces such as the macro sphere.

### 6.8.3 Hosting Events in Macro Spheres

Another aid to support coupling is to host deliberative events in the macro sphere. Committee members expressed that certain groups of individuals may not feel comfortable being part of the PHAC process. This was because the PHACs were held in a relatively formal way and the topics being discussed were quite complex. Complex medical jargon was often used, particularly in the vitamin D process. This was a previous criticism made by Ursu et al (2010). A few current examples of this complex language used by committee members are illustrated below.

"I think there's very strong physiological evidence that having a level between 25-50 is sub-optimal in terms of bone health"

"Vitamin D2 and vitamin D3 in our bodies are the precursors to the active hormone which is dihydroxyvitmin D which is written as 25-OHD and you'll have seen that in the evidence review. And D2 and D3 come from both the action of sunlight and foods, I think it's only D2 comes from plant foods"

This type of language may make certain groups of individuals uneasy, uncomfortable and unable to equally engage in the debates and arguments and this is problematic for inclusion (Young, 2001). In the NSP PHAC meetings, there was very little involvement from individuals who would normally access and use a needle/syringe service such as a current injecting drug user. A current user will have very different experiences and accounts to one who is in remission and reflecting back on their experiences. Including those with lived and also current experience is vital. It might to be too unrealistic to expect a current injecting drug user to attend such formal forums given their situation however their views and experiences are vital to the development of the guidelines. NICE may want to explore the possibility of extending the discussions hosted in the PHAC meetings into the macro sphere where other types of individuals can engage in less formal and structured deliberation. Hosting events such as focus groups that are attended by a few committee members may be a way in which the micro and macro deliberation can be linked. Committee members can discuss what they have been deliberating in the PHAC meeting and essentially 'check-in' with patient groups and service users about particular issues/topics, hear their views and opinions. This could help NICE better implement deliberative democracy and overcome the problem with inclusion. Hosting these deliberative events in other spaces and settings could potentially encourage different individuals who do not normally engage with NICE to participate. To ensure maximum inclusion, NICE might consider using patient videos where patients can talk about their views, experience and opinions which are viewed by committee members.

It is important that NICE take cognisance of the type of information and deliberation that is heard in these forums. Committee members expressed that NICE place heavy emphasis on members using evidence based reasoning and type I style discourse during the development of guidance. This perhaps deters committee members from drawing on the type II discourse they encounter outside the PHAC process for fear it might be rejected or make them look less professional. Some committee members did express that NICE might find it difficult to accept reasons based on experience and stories. However, these discourses still play an important role in deliberation and ensure that guidance is realistic and practical because it takes into account real stories and experiences. NICE should encourage committee members to draw upon stories, experiences and more emotive discourse they encounter in the macro sphere placing just as much importance on this type of discourse as they do with type I discourse. They could do this by allowing more space and time to deliberate social value judgements which relate to society rather than the scientific value of evidence. NICE could set their agendas differently giving active time to both scientific evidence and social value evidence.

One key role for these forums being hosted in the macro sphere could be to help discover and evaluate solutions to collective problems which emerge in the PHAC meetings. The groups could also set the deliberative agenda for PHAC meetings instead of this being ultimately driven by NICE. The consequence of this is that new or different issues are included on the agenda that NICE may not have considered. The agenda would also be driven by individuals potentially affected by decisions rather than professional or experts and this could encourage a completely different focus and inclusion of different types of evidence. This was something which committee members felt they had little influence over and was highlighted in the interviews. Committee members felt the framework was already fixed by NICE and that they had little influence over changing it. By allowing committee members and wider groups to

set the deliberative agenda (with the assistance of NICE) this could allow for a broader inclusion of issues. Settings where this type of deliberation could take place could be in services that would be potentially affected by the guidance, health centres and community centres. They might be classed as deliberative surgeries. These events being held in the macro sphere would be more supportive and informal for particular groups to take part in the process and to engage with other types of individuals they might not normally deliberate with such as senior level topic experts. This in turn could have a positive impact for all individuals involved in the deliberation as they could learn from each other's position, enhance their deliberative skills and be exposed to different/new information and perspectives. These recommendation would help NICE make better, deliberatively democratic guidance and improve their overall process to decision making.

#### **6.9 Conclusion**

This chapter set out to explore if NICE integrated macro deliberation with micro deliberation. There were some elements of macro deliberation occurring outside the PHAC meetings.

Committee members discussed the guidance they were involved in outside the meetings with other professionals and colleagues. The deliberation was described as being very informal and spontaneous which is typical of macro deliberation. However, the deliberation was private, face-to-face and ultimately lacked the wider dialogue evident in macro deliberation inclusive of the media, associations and wider networks. Committee members also placed very little significance on these instances. Due to this, the deliberation which was occurring outside the PHAC meetings could be classed as just an extension of the expert deliberation evident in the PHAC meetings suggesting that the positive elements of macro deliberation (inclusive of a variety of communication styles and diversity) were not fully present in the guidance development process.

Micro and macro deliberation should not be viewed as being two separate things and should be thought as "micro and macro scales that are interrelated" (Boswell, 2013, 626). This is because it is difficult to identify where one ends and one begins. There were a few examples of this blurring occurring in NICE. Where they do become differentiated is in terms of the functions they play and that although different, should remain integrated to help overcome the downfalls with each type. Spaces should "overlap and interconnect, so that a wide variety of ideas and opinions can be aired and assessed" (Boswell, 2013, 626). Normatively, this seems beneficial however this was lacking in NICE and appears to be practically challenging to implement. Having said that, there are a number of ways in which this can be done more effectively. NICE need to be better at actively combining these discourses through adopting techniques such as coupling and using bridge-builders.

Designed coupling should become embedded formally into processes and procedures in NICE to help disconnected sites become more integrated. This might mean that micro and macro deliberation is better balanced in the process as one cannot consciously ignore the other if they are formally coupled. Designed coupling could help NICE overcome the problems with institutionalising deliberative democracy potentially enabling it to reach a number of other voices addressing the scale issues, engage with individuals who might not traditionally access formal deliberative spaces such as lay citizens. Coupling would also address the issue of inclusion as those individuals would become engaged in a less formal manner with similar individuals. This could be a more inclusive approach taking cognisance of the skills that other participants possess. As an aid to coupling, NICE could also formally recruit bridge-builders into PHACs who have the responsibility of actively seeking the views and opinions of those in macro deliberative spheres. Bridge-builders would aid coupling as they could relay these discourses back to the PHAC meetings in a more formalised manner.

Networks like NICE appear to be relatively good at bringing together senior-level professionals and world leading experts to deliberate and make decisions rather effectively. They are ideal institutions which can easily foster micro conceptions of deliberative democracy and as a result of this type I deliberation is more likely to be the type of deliberation which emerges from such forums. This might be appropriate if networks such as NICE want to implement a relatively exclusive version of deliberative democracy and have limited connection to debates and dialogue occurring in the wider sphere. However, this makes NICE and similar networks open to criticisms such as being expert-led, exclusive and un-representative. These are characteristics which networks have been criticised for in the past (see chapter two, section 2.6). Deliberative democracy is evolving as a model to include other forms of communication. NICE may need to do this also. Given that NICE are committed to deliberating and considering technical judgements, as well as social value judgements, they need to be more inclusive of a diverse range of individuals and their voices. There needs to be much more opportunity for the macro and micro deliberation to influence each other in the decision making process of guidance development to ensure it is legitimate, representative and accountable.

## **Chapter 7. Conclusions**

#### 7.1 Introduction

Deliberative democracy is a model that aims to produce better, fairer and rational decisions through a particular style of deliberation which is underpinned by core norms, including reason-giving, common-good, inclusion and open-mindedness. It is a sophisticated model for organisations and decision making venues and fora to implement when compared to other forms of decision making such as aggregation which is based on voting and as a result can limit deliberation and the exploration of ideas, information and preferences. In contrast, deliberative democracy is talk-centric (Chambers, 2003) and focuses on the quality and content of arguments allowing preference exploration and change. There is growing interest in how deliberative democracy can be institutionalised in organisations; however, there are challenges in doing this. It is practically impossible to include all individuals affected by decisions in deliberation. It takes time, requires skill and knowledge. Due to social complexities, barriers and structural inequalities, not all individuals can participate in quality deliberation in a fair and equal manner. This issue can occur at the micro level due to the formality and structure of the spaces and also at a macro level because of the unstructured, informal nature of macro spaces.

To overcome these problems a potential solution is offered which consists of combining micro and macro conceptions of deliberative democracy (Hendriks, 2006). Micro conceptions are small, structured deliberative forums aimed at decision making (Hendriks, 2006). Due to the structural conditions of micro conceptions, discourse is rational, well-reasoned and prescriptive (type I). Micro-type I deliberation is aimed at decision making and occurs in formal, structured highly deliberative forums. Macro conceptions are less structured and informal spaces. Here, discourse includes lived experience, humour, rhetoric and emotive

language (type II). Macro-type II deliberation often occurs in networks, associations, pubs, cafes and the media and is aimed at agenda setting, opinion formation and preference checking. Both concepts however have weaknesses. Micro forums can be exclusionary and macro spaces are often un-structured and too remote from decision-making. Consequently, both should be combined to foster connections between the deliberative sites (Hendriks, 2006). This connection could encourage each forum and space to engage and influence each other and result in fairer, inclusive, and consequential deliberation because the crossfertilisation of discourses, ideas, information and knowledge can occur. This encourages individuals to consider their own preferences and those of others, justify their positions and arguments in a reasoned manner and be open-minded to potential preference change. Furthermore, this connection could result in better representation and democratic practice through presence and deliberation.

As detailed in chapter 2, section 2.4.3, Hendriks' (2006) combined model is largely theoretical. This is because she outlines the strengths and weaknesses of each conception of deliberation and how a combined model would be theoretically more robust. However, in her work, she does not provide any clear examples of how a combined approach might work in practice and what type of organisation or structure might institutionalise such a model. This thesis addressed this gap by exploring how a combined approach could be institutionalised by networks, and more specifically quangos and make a real-world difference.

Networks aim to include a range of individuals in decision making and at times base their processes on deliberation (Dryzek, 2011). This deliberation can occur at a micro level in small, contained, focused deliberative forums and also at a macro level where participants engage in more informal discussions about issues and topics. As such there is a link between deliberative democracy and how networks can operate. They are interesting to explore with

regard to combining micro and macro conceptions of deliberative democracy. As Davies (2004) highlighted networks were a response to governmental overload and as outlined in chapter 2, are used by government to solve complex policy problems in areas such as health-care, social services and the environment. They are often viewed as a necessary part of the decision making process due to expertise and knowledge that participants bring to the table (Hendriks et al, 2015, Fung et al, 2013, Hendriks, 2009). However, networks are criticised for being elite, unelected bodies where only those willing and capable of participating can take part (Papadopolous, 2012, Dryzek, 2011, Hendriks, 2009).

Quangos are part of the network structure and are forums which are made up of a range of participants (experts, professionals, citizens etc.). They are often deliberative and can embody deliberative democratic principles (Atkins et al., 2010, Daniels, 2008). They have the potential for encouraging dialogue between participants compared to other hierarchical alternatives and this dialogue is core to deliberative democracy. Consequently, quangos are a good case to explore because they have the potential to combine micro and macro conceptions of deliberation. This combination could possibly benefit quangos as they are often criticised for widening the democratic deficit and are characterized as exclusive, expert-led, private forms of government. By combining the two deliberative conceptions, quangos could have access to a diverse range of deliberative spaces and discourses, which would help those affected by decisions to be included in the processes. Given that NICE is inspired by deliberative democratic principles (Atkins et al., 2013, Daniels, 2008, Gutmann et al., 2002) and has made attempts to reform in response to the legitimacy criticisms associated with quangos, it was selected as a case study to explore if micro and macro conceptions of deliberative democracy could be combined.

The purpose of this chapter is to present the key conclusions which have emerged from this research. Firstly, the chapter briefly summarises the research problem, outlines the research aims and methods used to conduct the research. It then discusses the main findings and their importance for NICE. The chapter makes recommendations that NICE may wish to adopt to improve their public health guidance development process. Thirdly, it will discuss the implications for deliberative democracy and governance networks more widely. Fourthly, the chapter addresses the parameters of the research in this thesis and how future research might progress. It will conclude by offering final remarks including some personal reflections and thoughts about conducting this research.

## 7.2. Research questions and methods

Deliberative democracy requires organisations and other political and social decision making venues/fora which can institutionalise the core norms. However, it is practically challenging to achieve this. It is near impossible to scale-up deliberation to include all affected individuals in quality deliberation in a fair, meaningful and equal manner. Potential solutions to these barriers have been considered where deliberation would operate in micro forums and in macro spaces. Individually each conception works well however there are inevitable limitations; micro conceptions can be exclusive and macro conceptions unstructured and inconsequential. Combining the two conceptions may result in a more viable and inclusive model for organisations to institutionalise.

This study sought to explore whether Public Health Advisory Committees (PHACs) in NICE could combine micro and macro conceptions of deliberative democracy. PHACs were selected because committees are tasked with developing complex guidance spanning a vast range of public health topics that affect significant groups of society (i.e. pregnancy, weight

management, mental health, alcohol, smoking etc.). As such, the guidance must take into account scientific value judgements while also considering social value judgements. Social value judgements relate to ethical and moral issues and these are often explained through story-telling, lived and current experience which is a form of type II communication.

Scientific value judgements are about interpreting the quality and significance of the evidence available. This requires rational, well-reasoned and balanced discourse which is a style of type I deliberation. This essentially means that both types of deliberation should be evident in the process. Furthermore, PHACs are described in this thesis as a micro forum and therefore it is crucial that they connect to other types of deliberative spaces for the process to be democratically legitimate, representative and inclusive of those affected.

This study had four aims. These were to: 1) measure the deliberative quality of NICE PHAC meetings given that it is an example of a quango in a large healthcare network; 2) assess if macro deliberation occurs outside PHAC meetings; 3) assess if macro deliberation is integrated with the micro deliberation; and 4) explore if NICE, and other networks, can integrate the micro and macro deliberative deliberation to overcome the democratic issues they face.

To conduct this research, the DQI was used to measure the deliberative quality emerging from two NICE PHAC meetings which were focused on needle/syringe provision and vitamin D guidance. Secondly, semi-structured interviews were used to describe the macro deliberation occurring outside the PHAC meetings and explore if this deliberation was connected to the micro deliberation occurring in the PHAC meetings. The DQI data was analysed using SPSS and the semi structured interviews were thematically analysed.

#### 7.3 Findings and implications for NICE

A number of key findings and implications emerged from this research which will be detailed. Firstly, this thesis is the first to provide a measure of the quality of deliberation in the NICE public health guidance development processes contributing valuable, original and empirical evidence to the debate in deliberative democracy. In the absence of DQI data specifically focusing on the NICE PHAC meetings, this data contributes to a better understanding of how these meetings operate and can be used to compare other process in NICE such as the clinical guidance process from a deliberative democratic perspective. Furthermore, the formal link between the types of deliberation and conceptions of deliberative democracy is an original contribution. Type I and II deliberation tells us about the style of discourse used in networks. For example, are stories used? Is the discourse rational and reasoned? Micro and macro conceptions tell us more about the structure of networks i.e. is the network structured or unstructured, informal or formal? As such, this link has provided a much needed in-depth, descriptive insight into how quangos are characterised and function in health-care decision making and to other decision making bodies and topics.

PHAC meetings were classified as micro conceptions of deliberative democracy and the type of discourse used by committee members was similar to type I-expert deliberation. The deliberation occurring outside the PHAC meetings could be loosely classified as macro-type II deliberation. For example, the deliberation was very informal and spontaneous and it was based on opinion formation rather than decision making. However, it lacked a crucial element of macro deliberation which is broader public discourse and debate. For this reason, the discourse is in danger of being rendered as just an extension of the micro type I-expert deliberation that occurred in the PHAC meetings. As a consequence, the guidance process could be described as being elite driven, exclusive and unrepresentative of a range of

discourses and evidence like social value judgements. The study also found that the micro and macro deliberative sites were in general disconnected. This is also significant as it provides further support that there was little scope for other types of discourses from macro spaces to influence the more formal guidance development process. This essentially means the process could be described as being very insular and exclusive.

The findings in this thesis confirm that quangos that aim to embody deliberative democratic principles still find it difficult to institutionalise some of the core norms of deliberative democracy. This is particularly evident for the 'affected by all' norm: i.e. including all those affected by decisions in the process. In the guidance development process, certain groups of individuals were largely unrepresented, namely patients and citizens, both of which are key stakeholders. This is problematic as inclusiveness is core to the deliberative democratic model. If NICE want to produce better outcomes which are inclusive, representative and democratically legitimate, they need to widen their scope in terms of inclusion. To achieve this objective, NICE could embed a formal procedure to link disconnected micro and macro deliberative sites – i.e. designed coupling.

Designed coupling is an institutional mechanism and intervention used to formally link largely disconnected deliberative sites (Hendriks, 2016) and is relevant to NICE. This study is the first to provide practical ways in which NICE can make deliberative democratic improvements to their public health guidance process through designed coupling. It has been effective in fostering connections between citizens in participatory forums and elites in formal decision-making sites (Bächtiger, Setala and Gronlund, 2014, Papadopoulos, 2012, Setala, 2011). This is something which NICE, and similar organisations, should also aim to achieve and has been applied to a wide range of topics under deliberation (energy generation,

constitutions, and the introduction of the Euro). Therefore, there is no apparent reason why it could not be applied to health-care related issues.

Coupling would broaden the diversity of deliberation to ensure that both scientific and social value judgements are considered in NICE committees. PHACs could formally couple with the NICE Citizen Council which is a panel of citizens, similar to a mini-public, representing the demographic characteristics of the UK. They are responsible for providing a public perspective on moral and ethical issues that NICE need to consider when developing guidance. By connecting with the council, this could help NICE produce better public health guidance and outcomes that are more deliberatively democratic and not just of high deliberative quality. This is because PHACs would have access to a range of participants that are largely absent from the guidance development process i.e. citizens who could also be patients. This could ensure that a larger group of individuals are represented in the development of guidance.

It is within the Citizen Council that type II deliberation could be more evident. This is because the Citizen Council are responsible for deliberating ethical and moral issues.

Therefore story-telling, lived experience and emotive discourse could play a more prominent role in this space as it is common for citizens to use this form of communication (Steiner, 2012). This could possibly add another dimension to the NICE deliberation. However, the issue is that the council has no formal role in assisting with the development of public health guidance and act purely as an advisory body in ethical and moral issues. They have no interaction in the guidance process or engagement with committee members. This is paradoxical when NICE are claiming to include a range of participants in the development of guidance. By formally coupling PHACs and the Citizen Council, lay citizens and committee members could engage together in quality deliberation and produce better, fairer and more

inclusive public health guidance. This might also ensure that type I and II deliberation is better balanced in the process as one cannot consciously ignore the other if they are formally coupled.

NICE can also couple with macro spaces and this could further address the issues associated with including all those affected by decisions. Through coupling, NICE could have access to more deliberative spaces which operate in the macro sphere such as associations, the media and other networks. For example, NICE PHAC meetings could formally couple with another network such as the Scottish Intercollegiate Guidelines Network (SIGN). This network develops practice guidelines for the NHS in Scotland. The formal arrangement means that participants operating in each network could engage in dialogue with each other, share information, evidence and practice. This could give both networks access to a range of different voices and more individuals could be involved in the development of guidance.

Through coupling, NICE could better engage with those who do not normally participate in more formal deliberative forums such as citizens, front-line workers and service users.

Connecting with macro spheres, could help NICE include those individuals described above in a more informal way by allowing them to participate in forums which may be more suited to their skill and level of understanding of the issues. This might also address the issues with equal and fair participation.

It is likely that coupling will need facilitated in some capacity. One way in which this could be done is through utilising bridge-builders. These are individuals key to connecting deliberative forums and spaces and could aid the process of coupling. The role of bridge-builders in aiding coupling is an original concept developed in this thesis and has not been previously applied to NICE or the public health guidance process. These specifically

recruited individuals can act as conduits for deliberation and may help NICE access and engage better with the deliberation that occurs in the macro sphere. For example, bridge-builders could be members of different networks and associations (macro sites) as well as PHACs (micro forums) and have a formal role in sharing and spreading information, evidence and dialogue across a range of fora.

Not all individuals will want to take part in a formal guidance development process, but that does not mean their discourses should not be heard. NICE need to be more proactive in the macro sphere rather than simply assuming that those voices will come to them. Bridge-builders, employed by NICE, could facilitate and record informal face-to-face discussions with lay members of the public about their experiences of certain issues, gather opinions and check preferences. They could also set up topic stalls in the public arena for example in community and health centres where individuals can learn about the different guidance NICE are developing. This can provide those individuals with the opportunity to learn, express their thoughts, opinions and feelings in a relaxed and informal manner. This information can then be analysed, themed and taken to the PHAC meetings for consideration. This provides lay citizens with a less intimidating space where people may feel more comfortable and better able to engage in the process.

It is no easy task to develop guidance and this was observed during PHAC meetings. The process is long, intense and committee members scrutinise complex evidence and information. However, NICE may need to recognise that not enough has been done to access the discourses of those who might not normally participate as a committee member. Experts do not have a monopoly on being correct and are often far removed from the realities of living with a medical condition or how guidance might impact on the workforce doing their job at a front-line level. NICE need to be more proactive in including those under-represented voices

and opinions in the guidance development process. This could be achieved through coupling and using bridge-builders.

Hendriks (2006) ultimately failed to provide clear practical examples of how micro and macro conceptions of deliberation could be linked. The original findings and recommendations offered in this thesis are the first to provide NICE and other quangos, with theoretically informed practical, but ways in which they can improve their guidance development process and produce more democratically deliberative guidance that is not excessively dominated by experts. These findings are not just relevant for NICE. They are also significant to deliberative democracy and governance networks more widely.

#### 7.4 Implications for Deliberative Democracy and Governance Networks

This research extends Hendriks' debate on a combined micro-macro approach by applying this to quangos. The findings ultimately demonstrate that one institution cannot realistically achieve all the standards of deliberative democracy and as a consequence both micro and macro conceptions are critical and relevant for institutionalising the model. Each sphere has a role and function and this division of labour would help deliberative democracy overcome some of the challenges they face; division allows flexibility. A flexible deliberative system recognises that social inequalities exist and that not all citizens need to have the same level of skills/knowledge to be able to participate (Chambers, 2017). While it recognises the important role of experts, these experts should be challenged and scrutinised by citizens (Chambers, 2017). This principle should also apply to citizens and scrutiny should therefore be a two-way process. Lastly, a deliberative system includes a variety of deliberative styles and not just rational discourse (Chamber, 2017). This variety aims to ensure that democratic deliberation can be achieved because citizens and experts can communicate more effectively

together through different styles of communication and are not restricted. Micro and macro concepts should therefore co-exist and be integrated as part of a flexible deliberative system to ensure deliberative democracy can be institutionalised in real-world structures such as networks and quangos.

However, there was limited evidence of a variety of types of discourse being used in the NICE PHAC meetings as members were typically senior-level experts from the medical profession their discourse style was rational and formal. This is an important finding because it suggests that at times networks may find it practically difficult to change just because of their composition. Consequently, it may not be feasible for networks to include other types of deliberation (type II) in the more formal process but this style of discourse still needs to be included elsewhere if it is absent from formal processes. Overall, networks need to make a conscious effort to form stronger links with other parts of the wider deliberative system (Dryzek, 2011). This is because each part of the system plays a role and has a function. If the function of the network is to "identify the best possible answer to technically complex questions it is reasonable to organise a deliberative meeting among experts" (Chappell, 2010, 301). Indeed, it would be testing for non-experts to meaningfully and equally engage in this type of expert focused deliberation. However, when developing guidance, other complex issues arise such as moral, social and ethical issues. These need to be addressed too. We should not expect networks to carry out all these functions and involve a range of participants that may not be suited to the structure or format. Other deliberative spaces in the macro sphere could be coupled to networks where participation is more suited to a broader range of individuals.

It is not necessarily a new concept that the norms of deliberative democracy ought to be relaxed (Elstub, 2006, Sanders, 1997, Young, 1996) but this thesis provides further empirical

evidence to support this argument. This would make the model more inclusive and viable.

Relaxing the core norms of deliberative democracy to include type II deliberation such as stories, rhetoric and emotional discourse and self-interest could encourage participation from a wider range of individuals and therefore deliberation could be more inclusive and equal.

Deliberative democracy needs to evolve as a theory and become more aligned to real-world practice in order for it to be implemented in organisations.

If deliberative democracy is to be more tolerant of other forms of communication and not just type I deliberation then this also needs to be captured methodologically. Despite the DQI being described as a "flexible framework" (Steenbergen et al, 2003, 42) it mainly focuses on the standards of deliberative democracy which are more typical of micro deliberation such as an emphasis on rationality and justification of arguments. With the rising importance of macro conceptions of deliberative democracy and type II discourse these standards must also be captured and measured. These conceptual developments in deliberative theory must be reflected in empirical measurements (Bachtiger et al., 2009). Attempts have been made to do this; however critics such as Gould (2009) argue that a DQI-style approach does not capture the public essence of macro deliberation. For deliberative democracy to evolve successfully and maintain relevance in today's society, effective and appropriate measures need to be developed.

Currently, there exist two broad ideal types of deliberation. Type I which is focused on rational discourse and on process; and type II which includes alternative forms of communication and takes a prime focus on deliberative institutions and outcomes (Bachtiger et al, 2009). However, there is also the potential for a *type III deliberation*. This would include deliberation which was rational, reasoned and justified but at the same time accept that story-telling, lived experience and self-interest are also relevant forms of evidence which

decisions can be based on. Scientific, technical and medical evidence would also feature in this style of deliberation. It differs from type II deliberation as it would also explore the way in which deliberation is delivered i.e. through tone and body language. These are important cues which can effectively change the meaning of discourse. Type III might also take into account the environment in which deliberation occurs as this can have an impact on how individuals participate in deliberation. Acting as a middle ground between type I and II, networks could include type III deliberation in decision making providing the conditions are right.

For example, networks should be more plural by including a mixture of individuals in the process and encourage discursive inclusion (type I, II and potentially III). They can achieve this through coupling with other deliberative spaces such as mini-publics like citizen juries and deliberative polls. This is particularly relevant for networks which are de-coupled as it can offer some procedural and functional guarantee to formally link relevant deliberative spaces and participants in deliberation. This is because mini publics are "are participatory processes designed to elicit informed and considered public input from people who would not normally engage in conventional consultation or advocacy" (Hendriks, 2016, 47). This could make decision making processes in governance networks, and quangos more accountable, inclusive and fair because coupling would be formally embedded in the process with links that are not tokenistic or symbolic.

Networks can encourage more informal dialogue in a variety of spaces in the public arena. A key role for these deliberative events could be to help discover and evaluate solutions to difficult or testing problems which emerge in the network. Here, members of society could put issues onto the formal network agenda instead of being ultimately driven by the network or quango, which is often the case. New or different issues could be included which may not

have been previously considered by the network. The agenda would also be driven by individuals affected by decisions rather than professionals or experts and this could essentially re-frame the debate.

Networks that have like-minded individuals involved in the deliberation and decision making are more likely to have a stable discourse. This can prevent contested discourses being considered and therefore the process can be deemed ineffective as things are rarely challenged. Networks could avoid this stabilized discourse by ensuring that different experts, professionals, citizens and patients are brought together to meaningfully deliberate issues in a balanced way.

Finally, there also must be some shift in their accessibility. Networks often host their deliberation removed from the public arena and this hinders access, transparency and scrutiny. Some are not very visible and need to be more public. Even when they are open to the public, as with the case in NICE, not many individuals attend. They can be better at connecting to the public sphere by utilising social media platforms such as twitter to raise awareness that they are open to the public and to connect and generate interest in the topics they are deliberating.

#### 7.5 Limitations and Next Steps for Future Research

While the research aims were successfully achieved, there are a number of limitations to address. Only two PHAC processes were observed for this research and therefore the results cannot be applied to the whole of NICE or all guidance development processes. Furthermore, the project only included one UK based case study and this is a limitation of the research as the findings cannot be generalizable to all UK or international quangos. Secondly, it was not

possible to interview participants external to the PHAC process and as a result only committee members were interviewed. It would have been interesting to interview other individuals engaging in the macro sphere to trace how far the macro deliberation extended. The study did not analyse mass and social media covering the topic areas plus broader civil society activity. However, this was not a research aim for this particular study.

Future research could measure the deliberative quality of more PHAC meetings to have a deeper insight into the overall deliberation emerging from the public health guidance development process. NICE develop a range of different types of guidance and it would be interesting to compare the DQI data with data from a different guidance process such as clinical guidance to assess similarities / differences in the deliberative quality.

The DQI data could also be compared with a similar epistemic community or healthcare network such as the Scottish Intercollegiate Guidelines Network (SIGN) who have a similar remit as a comparison study. It would also be interesting to compare the data against another quango in a different policy area covering environmental issues for example.

This research focuses on two types of deliberation; type I and II. The DQI does not measure non-verbal cues such as body language or tone. Future research could explore a non-verbal dimension of deliberation, where a type III is developed and explored. The type III could report on gestures, tone and body language and this would provide a very different descriptive element to the DQI. For example, it may be the case that a particular speech act was measured as being respectful but it was followed by an eye-roll or a smirk inferring that it was not truly respectful. This could change the overall quality.

Lastly, further research might focus on interviewing those engaged in the wider macro sphere to trace the deliberation and explore if NICE related deliberation extended further than committee members and their close networks.

#### 7.6 Final comments

NICE have a difficult job developing a range of health care related guidance which is reflective of issues and evidence while being sensitive to and inclusive of a range of audiences. Managing this is no easy task given the volume of guidance they are required to develop and continually review. They have tried to strike a balance between basing their guidance on the best available evidence and at the same time including a wide range of participants in the process through adopting deliberative processes. This is an achievement and good practice which other networks could follow but this thesis has demonstrated that there are challenges with striking that balance.

NICE are good at facilitating deliberation between experts and senior-level professionals but struggle with including other types of participants in the more formal processes such as citizens and front-line workers. This means their discourses were largely excluded. Some might argue that it might not be appropriate that, citizens for example, participate in an epistemic community (Irvin and Stansbury, 2004) because it is not easy to achieve, is inefficient and ineffective. In the development of guidance, there does need to be a high level assessment of evidence between those capable of doing so (experts and professionals) and it might not be feasible that others can or should meaningfully engage in that particular part of the process. However, the development of guidance should not be left to elites or the privileged few. They are not always right, balanced, rational or well-reasoned. At some point, other voices do need to be included to ensure the process and outcomes are inclusive

and representative. Further to this, experts, and others, need to be challenged on their arguments and positions. This is core to deliberative democracy. NICE need to be better at linking with other voices and deliberative spheres because without that connection they are in danger of being just another expert led network. This research has provided insights into two public health guidance development process in NICE and in doing so has opened up some interesting discussion about the feasibility of a range of participants being able to really engage with each other in meaningful deliberation and the ability of networks to combine micro and macro deliberation.

When I was first introduced to deliberative democracy it sounded an ideal model which produced better outcomes when compared to aggregation. This is because it is based on deliberation which encourages individuals to voice their opinions and reasons for their decisions. It is a model which has educational benefits as it exposes participants to different perspectives that they may have never considered before. It encourages reflection and the weighing up of information. However, there are clear barriers to institutionalising deliberative democracy. Conducting this research has allowed me to understand the complexities of bringing together different people from different backgrounds to deliberate meaningfully. Professionally, I have been a participant of such processes and witnessed how difficult it is to integrate voices from different people, who have competing agendas, into something meaningful. Getting a range of participants to engage in decision making or deliberation is challenging but networks need to pro-actively open up and hear those voices rather than assuming they will come to them. There is currently a rise in political engagement and a greater appetite to participate in British affairs. For example, in 2017, voter-turnout was the highest it has been for 25 years for a general election (The Guardian, 2017). Individuals clearly want to have their say on important matters that affect them. Networks,

including NICE, should engage with this appetite and get citizens, and others, involved in debates that are highly relevant to them.

Undertaking the research has also made me question my original position on deliberative democracy which was overwhelmingly positive. Deliberative democracy needs to be more grounded in everyday lives and experiences. Some attempts have been made to do this such as including other forms of communication but there are problems with this. If deliberative democracy relaxes too much then it could become a model which is completely different from its origins as the more difficult norms to implement may be disregarded. Consequently, that could have an impact on the legitimacy of deliberation and what is then practiced is a different version of the intended model. It seems as if deliberative democracy is currently stuck between a rock and a hard place. The rock being that it has a core set of theoretical norms and the hard place being that institutions find it tough to practically implement these norms. This thesis has highlighted the challenges associated with institutionalising deliberative democracy in an organisation which already has some fundamental principles embedded in their structure such as citizen participation and deliberative mechanisms which allow social value judgements as well as technical judgements to be considered. If NICE struggle to properly institutionalise deliberative democracy, how will others? Deliberative democracy is an ideal model but it needs to be realistic, user-friendly and at the same time ultimately improve decision making. Through piloting some of the solutions offered in this thesis, networks and quangos can now explore ways in which a more viable and inclusive combined approach can be institutionalised. Ultimately this is positive for democratic decision making as it could operate in a variety of deliberative spaces ensuring that a range of voices are included and integrated in quality, meaningful deliberation delivering better outcomes.

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## **Appendices**

## **Appendix 1 – Formal Research Request Letter**

Lauren Johnston University of the West of Scotland School of Social Sciences Room L113 Paisley Campus PA2 XBE

#### Dear Professor Mike Kelly

Following our meeting on Wednesday 27th February 2013 I am writing to the National Institute of Health and Clinical Excellence (NICE) to formally request access to the Public Health Advisory Committee meetings for the purposes of data collection for my PhD. I wish to begin my data collection in June 2013, if this is at all possible.

I intend to record and observe the Public Health Advisory Committee (PHAC) meetings which are held in public at NICE. I will transcribe the audio and apply a coding framework which will measure the deliberative quality of the discourse. It is my intention to record two or three meetings. The topic of the meeting is not necessarily of importance however I do have a professional interest in public health issues surrounding substance misuse. I would be grateful if I could observe and record meetings which take substance misuse into account during the deliberation process.

As discussed, I would like to record the meetings by linking into the speaker system which is in operation at NICE and to record the audio on a C.D. It would be useful if I could pilot this process before my fieldwork commences. I would greatly appreciate if you could confirm whether the speaker system in NICE will record onto C.D.

It is not my intentions to change the dynamics of the meetings and I do not anticipate that my fieldwork will be in any way intrusive. My aim is to record audio and observe the meetings. The members of the PHAC will be anonymized in the PhD. The data which is collected will be accessed by my PhD supervisor, Dr. Stephen Elstub and me. The data will be stored in a locked filing cabinet within the University and will be destroyed after the PhD is successfully completed.

As requested, I have enclosed the following document;

- A brief research proposal
- A letter from Dr. Stephen Elstub
- A letter granting Ethical Approval
- A consent form for the PHAC members

If you have any further question please do not hesitate to contact me or my supervisor. I look forward to hearing from you soon

Yours Sincerely

L. Johnston

#### Appendix 2 – Data Submission Form for Research Register

#### Data submission form for Research Register

1. Title of the project and brief description

Fostering a Deliberative Democratic environment: an integrated network approach to decision making in the National Institute of Health and Clinical Excellence (NICE).

This PhD project explores the extent to which the core norms of deliberative democracy can be observed in the decision-making processes of NICE and its related policy networks. The data will be collected by recording two/three Public Health Advisory Committee (PHAC) meetings held in public using audio recording equipment. The audio will be transcribed and a coding framework will be applied to the discourse which will measure the deliberative quality of the discourse. Interviews will also be conducted with participants in the policy network to understand the nature of the communication outside of the formal meetings.

2.	Please identify	v the lead	team/centre	involved i	n this	project	from NIO	CE

a.	Centre	for Health Technology Assessment	
	i.	Technology Appraisals	
	ii.	Medical Technologies Evaluation	
		Programme	
	iii.		
	iv.	Diagnostics Assessment Programme	
	v.	Interventional Procedures	
	vi.	Research and Development	
b.	Centre	for Clinical Practice	
c.	Centre	for Public Health Excellence	$\boxtimes$
d.	Evider	nce Resources Directorate	
	i.	NHS Evidence	
	ii.	<b>Guidance Information Services</b>	
	iii.	User Research Team	
e.	Health	and Social Care Directorate	
	i.	NICE Pathways	
	ii.	Quality Systems	
	iii.	Implementation	
	iv.	Accreditation and QIPP	
	v.	PPIP	
	vi.	Fellows and Scholars	

3. Please provide the name and institutions of all those involved in the project (internal and external)

The NICE Public Health Advisory Committee members for the NSP guidance will be involved in the project. Names of the members have not been disclosed to the researcher. Professor Mike Kelly has been involved in this project providing an access link to NICE. Externally Dr. Stephen Elstub of the University of the West of Scotland (UWS) will be involved in the project as the Principal Supervisor. Professor

4. Please provide the start date (mm/yyyy) and the anticipated finish date (mm/yyyy) of the project

	will be completed	by October 2016.	egan in Octo	ber 2010 and	
5.	Please classify your p	project into one of the follow	wing categor	ries	-
	c. d. e. f. g. h.	Data Collection Evidence Synthesis Other appraisal-assessment Health utilities Modelling and economic of Engagement and decision Process Implementation Policy and Practice International comparisons	evaluation making	ogy	
6.	Please classify your project in <u>one</u> of the following type of research activities (Please refer to the attached document on defining research)				
	b. c.	Research Audit Service evaluation (including service development and quality improvement projects)		Go to 7 Go to 7 Go to 7	
7		Literature review		Go to 10	
1.	Does your project req a. b. c.	Yes No Unsure			
8.	If yes, who is respons	ible for gaining ethical app	roval?		
	a. b.	Staff from NICE External collaborators			
9.	Has the ethical approx	val been obtained for this p	roject?		
	a. b. c.	Yes (please attach a copy the ethical approval letter) No Not Needed			

10. Please attach any relevant documents for the project (e.g. research protocol, publication)

If you have any queries related to submission of the research project, please contact Bindweep Kaur at <a href="mailto:bindweep.kaur@nice.org.uk">bindweep.kaur@nice.org.uk</a>

Thanks for your submission

## Appendix 3 – PHAC Ethics Material for Recordings

## PHAC CONSENT FORM

Name of PhD researcher: Lauren Johnston

Fostering a Deliberative Democratic environment: an integrated network approach to decision making in the National Institute of Health and Clinical Excellence (NICE)

Name of Principal Supervisor: Dr. Stephen Elstub
✓ Please TICK each box below <b>Ψ</b>
I confirm that I have read and understand the information sheet for the above research project, or have had it explained to me, and have had the opportunity to ask questions.
I understand that some meetings will be recorded for transcribing.
I understand that I will remain anonymous and that my name will not be used in the analysis or final thesis.
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason or legal rights being affected.
I agree to take part in the above research.
Name of committee member Signature Date

#### Appendix 4 - Information sheet – Recording

# **Information Sheet for Public Health Advisory Committee Members Observation and Recording**

Study Title: Fostering a Deliberative Democratic environment: an integrated network approach to decision making in the National Institute of Health and Clinical Excellence (NICE)

#### What is the purpose of this study?

The research is interested in how people interact within policy networks. NICE have been chosen as they are an example of a healthcare policy network. The project is specifically interested in the development of public health guidance. It is important that public health guidance is developed democratically, legitimately and that all voices are given an opportunity to influence the direction of the public health guidance. This project aims to explore these issues.

#### How long will it last?

This field work is part of a doctoral study (supervised by Dr Stephen Elstub at the University of the West of Scotland) that will last, in total, until around the end of 2015. However, the data gathering stage, in which you are invited to be involved, will last for about 3 guideline meetings.

#### Why have I been chosen?

You have been invited to take part because you are a member of a NICE Public Health Advisory Committee. This study aims to listen to debates which occur in public health guidance meetings and explore the deliberative quality of the debates.

## Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason and to withdraw any information to have provided.

#### What will happen if I take part?

The researcher will attend 3 meetings and observe the group while they deliberate and discuss the development of the public health guidance. The process in which the group normally follows during these meetings will not be changed or altered in any way. The researcher will record the discussions that take place so that the discussions can be coded at a later date.

#### What are my responsibilities if I decide to take part?

There will be no extra responsibilities asked of you if you decide to take part, out with the responsibilities outlined by NICE. You can withdraw from this study at any time. If at any point during the meeting you decide you no longer want to continue, you can stop the meeting without giving a reason.

## What are the benefits of taking part?

You will not benefit directly from this study. However, there may be some wider benefits of dedicating your time and resources to this study in the long term. By taking part in this project you will contribute to a deeper understanding of how policy networks operate. The data gathered will be used to explore the possibility of enhancing decision making processes in healthcare; making them more democratic and legitimate. The data will be used to develop

general guidelines on how to democratically improve the way NICE and related public authorities interact with stakeholders in decision making.

#### What about confidentiality?

All of the information that is collected about you (names, organisation, role) during the course of the research will be kept strictly confidential. Any information about you that leaves the University will have your personal details removed so that you cannot be recognised from it. You will never be quoted and any items you bring with you to the meeting will never be reprinted or displayed unless you give your express written permission – you do not have to consent to this in order to take part in the study.

#### What will happen to the results?

The results of this study will make up part of the doctoral thesis submission by the researcher. Some results may also be published, either before the thesis is submitted, or at a later date.

## Who is organising and funding this study?

This study is organised by Lauren Johnston and Dr Stephen Elstub of the School of Social Sciences at the University of the West of Scotland and is funded by both the University.

### Who approved this study?

The School of Social Sciences, University of the West of Scotland Ethics Committee provided this study with its ethical approval.

## Who should I contact with any queries or complaints?

If you have any queries/complaints regarding this information sheet, in the first instance please contact:

Lauren Johnston University of the West of Scotland Paisley PA1 2BE

Tel: **07745541647** 

Email: LAUREN.JOHNSTON@UWS.AC.UK

Thank you for your help.

#### **Appendix 5 - Covering Email – Recordings**

#### Dear PHAC members

My name is Lauren Johnston and I am a PhD student at the University of the West of Scotland. I am writing to you in order to inform you about my research which is interested in NICE and the decision making processes that take place in PHAC meetings. I am hoping to record a series of PHAC meetings as part of my data analysis. I have attached an information sheet which provides more information on the project.

As a member of the PHAC I am asking for your consent to record a number of different meetings. The information sheet will hopefully answer some important questions you may have about this research and importantly how this data will be used. As a member, you will remain anonymous in the research and you will not be identified in the research. I have attached a consent form which I hope you may be able to fill in and return as soon as possible.

With best wishes Lauren Johnston

## **Appendix 6 - PHAC Ethics Material for Interviews**

#### **Consent form**

Participant's Name:

## Interview CONSENT FORM

Title of Project: Fostering a Deliberative Democratic environment: an integrated network approach to decision making in the National Institute of Clinical Excellence

Name of Researcher: Lauren Johnston

Please initial box. You do not have to consent to part 5 to take part in this study.

1	I confirm that I have read and understand the information sheet	
	dated 19/06/12 (version 1.1) for the above study and have had the	
	opportunity to ask questions.	
2	I agree that this interview will be recorded and transcribed by the	
	researcher.	
3	I understand that my participation is voluntary and that I am free to	
	withdraw at any time, without giving any reason, without my legal rights	
	being affected.	
4	I agree to take part in the above study.	
5	I understand that I am entitled to see a copy of the initial analysis of the	
	information I provided during the discussion and I do wish to see a copy	

Please complete two copies of this form and keep one for yourself and give the other to the researcher. Please remember to complete your name, signature and the date over the page.

## Name of Participant:

Signature:

Date:

Name of person taking consent (if different from researcher):

Signature:

Date:

Name of researcher: Lauren Johnston

Signature: Lauren Johnston

Date: 3/3/14

#### **Appendix 7 - Information Sheet – Interviews**

## **Information Sheet for Public Health Advisory Committee members Interviews**

Study Title: Fostering a Deliberative Democratic environment: an integrated network approach to decision making in the National Institute of Clinical Excellence

#### What is the purpose of this study?

The research is interested in how people interact within policy networks. NICE have been chosen as they are an example of a healthcare policy network. The project is specifically interested in the development of public health guidance. It is important public health guidance is developed democratically, legitimately and that all voices are given an opportunity to influence the direction of the public health guidance. This project aims to explore these issues.

#### How long will it last?

This field work is part of a doctoral study (supervised by Dr Stephen Elstub at the University of the West of Scotland) that will last, in total, until around the end of 2015. However, the data gathering stage, in which you are invited to be involved, will involve a telephone interview which will last approximately 1 hour.

#### Why have I been chosen?

You have been invited to take part because you are a member of a NICE Public Health Advisory Committee (PHAC) or are involved externally in the wider policy network associated with the development of the guideline. This study aims to gain an understanding of how actors within different networks engage with one and other and how these interactions can influence the direction of public health guidance.

#### Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason and to withdraw any information to have provided.

#### What will happen if I take part?

The researcher will contact you directly via telephone or email and arrange a suitable time to take part in an interview. Once a date has been agreed, the researcher will contact you on the date and will record the interviews so that the interview can be transcribed and analysed at a later date.

#### What are my responsibilities if I decide to take part?

There will be no responsibilities asked of you if you decide to take part. The researcher will contact you and arrange a suitable time with you for the interview. You can withdraw from this study at any time. If at any point during the meeting you decide you no longer want to continue, you can stop the meeting without giving a reason.

#### What are the benefits of taking part?

You will not benefit directly from this study. However, there may be some wider benefits of dedicating your time and resources to this study in the long term. By taking part in this project you will contribute to a deeper understanding of how policy networks operate. The data gathered will be used to explore the possibility of enhancing decision making processes

in healthcare; making them more democratic and legitimate. The data will be used develop general guidelines on how to democratically improve the way NICE and related public authorities interact with stakeholders in decision making.

## What about confidentiality?

All of the information that is collected about you (names, organisation, role) during the course of the research will be kept strictly confidential. Any information about you that leaves the University will have your personal details removed so that you cannot be recognised from it.

You will be quoted however these quotes will be anonymised and any material that you discuss will not be displayed unless you give your express written permission – you do not have to consent to this in order to take part in the study.

#### What will happen to the results?

The results of this study will make up part of the doctoral thesis submission by the researcher. Some results may also be published, either before the thesis is submitted, or at a later date.

## Who is organising and funding this study?

This study is organised by Lauren Johnston and Dr Stephen Elstub of the School of Social Sciences at the University of the West of Scotland and is funded by both the University.

#### Who approved this study?

The School of Social Sciences, University of the West of Scotland Ethics Committee provided this study with its ethical approval.

## Who should I contact with any queries or complaints?

If you have any queries/complaints regarding this information sheet, in the first instance please contact:

#### **Lauren Johnston**

University of the West of Scotland

**Paisley** 

**PA1 2BE** 

Tel: **07745541647** 

Email: <u>LAUREN.JOHNSTON@UWS.AC.UK</u>

Thank you for your help.

## **Appendix 8 – Interview Schedule**

Age	<b>16-24</b> □	<b>25-44</b>	<b>45-64</b> □	<b>65</b> + □	
What is the name of your organisation? What is your gender?		ntion?	Write organisation		
		<b>Male</b> □	F	'emale □	
organ  How long has y	rief outline of wha isation does? our organisation led with NICE?				
what is	your job title?				

<u>I am now going to ask some questions about your involvement in NICE and your experiences</u>
<u>of being consulted as an organisation.</u>

## **General**

How often are you consulted by NICE?

Why are you consulted by NICE?

Do you contact or lobby NICE as an organisation, if so how do you do this?

At what stage in the process are you consulted/lobbied by NICE?

What do you think your organisation brings to the guideline development process? What type of information does your organisation bring to the process? For example, stories, experiences, statistical evidence, facts?

Is this information taken into account? If so can you give evidence of this, if not why do you think this is the case?

## **Density**

How many other groups do you contact during the guideline development process? Can you give me an example of any organisations you contact and how often you contact them?

How do you contact them?

Do you think the guideline development process is inclusive? If so can you give evidence of this, if not why do you think the process is not inclusive?

Are there organisations that should be consulted, but are not? Why is this the case?

NICE aim to bring a range of people together to speak to each other and listen to each other, does this process work? If so in what ways, if not how can it be improved?

#### **Betweeness**

Why do you speak to other organisations during the guideline development process? If you don't speak to other groups, why is this?

Do you find speaking to other groups beneficial in the process of guideline development, if so why?

Do you think it is important for experts, clinicians, representatives, organisations and lay citizens to engage with one and other during decision making? If so why? If not why?

#### **Centrality**

Is one particular type of group/actor given more opportunities to speak during the process? If so why is that the case?

Do you feel respected as an involved actor in this process?

Is there a type of information that is given more respect during the process, for example do you spend more time discussing statistical evidence and factual information than listening to stories and real-life experiences?

This is the end of the interview. I would like to thank you for taking part in the interview.